FINAL SUBMISSION BY THE CARE & SUPPORT CONSULTATION GROUP
STANDARDS-BASED ASSESSMENT OF UNGASS HIV/AIDS CARE & SUPPORT INDICATORS

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1. SUMMARY OF CONSENSUS RECOMMENDATIONS FOR UNGASS INDICATORS IN HIV/AIDS CARE AND SUPPORT IN NON-CLINICAL SETTINGS

IMPORTANT NOTE: The following recommendations are of *equal* importance. The order in which they are presented simply reflects the logical order of: firstly, addressing existing UNGASS indicators (recommendations 1-3); secondly, presenting an existing indicator with a proven track record for inclusion in the UNGASS indicator set (recommendation 4); and, finally, recommendations of general relevance (recommendations 5, 6).

RECOMMENDATION 1.
UNGASS INDICATOR 10: Percentage of orphans and vulnerable children whose households received free basic external support in caring for the child.
This UNGASS indicator should be modified to "Proportion of eligible households who received economic support in the last 3 months".

Rationale:

UNGASS indicator 10 was measured through population-based surveys such as DHS, AIS and MICS. Questions to construct this indicator were recently removed from these surveys due to the following key challenges: (a) measuring 'external support' -as per the broad definition included in the indicator, required a large number of survey questions and thus substantial interview time; (b) interpretation of the data in terms of support for households affected by HIV and AIDS was difficult; and (c) using proxies of AIDS affectedness such as chronic illness in households have generally been difficult and the links to HIV and AIDS have often been weak as are associations with poor developmental outcomes. However, there is still a critical need to measure care and support services directed to the household level. The modified indicator reflects the growing international commitment to HIV-sensitive social protection as a key strategy in combating HIV and AIDS. Tracking coverage of support for orphans and children within poor households remains a developmental priority as reflected in the strategic plans of countries and of international organizations/donor agencies. The modified indicator overcomes the data collection and interpretation challenges of the existing UNGASS indicator 10. It is of programmatic relevance mostly to countries with high HIV prevalence and to a range of international organizations/donor agencies; hence, it supports the global indicator harmonization agenda.

RECOMMENDATION 2.
UNGASS INDICATOR 12: Current school attendance among orphans and among non-orphans (10–14 year olds, primary school age, secondary school age).
This UNGASS indicator should be continued to be measured as per its current specifications but with an expansion in age groups. The following issue for potential indicator improvement should be investigated for the next UNGASS indicator revision round: the global significance and data collection feasibility of a measure of 'school attendance' that extends beyond the current 'attend school *at any time* during the school year'.

Rationale:

Based on analyses of recent indicator data for a range of countries, UNGASS indicator 12 continues to be a sensitive measure for identifying disparities between orphans/non-orphans. This is also a Millennium Development Goals (MDG) indicator. Hence, continued measurement of this indicator –without modification, is worthwhile, feasible (i.e., using existing data collection tools) and allows for much needed trend data linked to both UNGASS and MDG

commitments. However, an expansion in age groups is recommended. In addition to 10-14 year olds, data should also be included on orphans/non-orphans of primary school age and lower secondary school age. The current age range (10-14 year olds) cannot be correlated to primary school age or to lower secondary school age which makes it difficult to work with in educational settings. In addition, attendance rates often show a sharp decline from primary to secondary school (especially when primary school education is compulsory); hence, the children currently included in the numerator and in the denominator are subject to different attendance prevalence.

In addition, the proposed investigation for indicator improvement needs to address the following issue: the current measurement of 'school attendance' is a poor proxy for what can be considered 'adequate' attendance; however, a 'minimum required attendance' would need to be agreed (often this is considered to be not less than 80% of class time) and the feasibility of such a measure as a 'standardized global indicator' for which it is feasible to collect good quality data needs to be carefully considered. This is considered of utmost importance, but a multi-stakeholder, standards-based, consensus process for identifying an existing indicator with proven track record or for developing and pilot-testing a new indicator cannot be completed within the time line of the current UNGASS indicator review. The modified or new indicator also needs to be in line with the new MDG which are currently under review.

RECOMMENDATION 3.
UNGASS INDICATOR 2. NATIONAL COMPOSITE POLICY INDEX (sub-set of questions relevant to HIV/AIDS care and support in non-clinical settings).
This UNGASS indicator should be continued to be measured with minor modifications only.

Rationale:

The NCPI is applicable to all countries, is the highest reported UNGASS indicator (i.e., evidence of data collection feasibility), and encourages a collaborative process among in-country stakeholders which has yielded important benefits beyond UNGASS reporting (as per experiences reviewed at country level). Substantial trend data already exist which is important to conserve over the next UNGASS reporting rounds. Hence, the NCPI questions relevant to care and support were modified only where strictly necessary to reflect new programmatic developments (i.e., reflecting a fully comprehensive approach to care and support and endorsing care and support as an essential programmatic component in its own right rather than a sub-component of HIV/AIDS treatment).

RECOMMENDATION 4.
NEW UNGASS INDICATOR: PERCENTAGE OF WOMEN AND MEN AGED 15-64 EXPRESSING ACCEPTING ATTITUDES TOWARDS PEOPLE LIVING WITH HIV.
This existing indicator with a proven track record should be included in the UNGASS indicator set.

Rationale:

Stigma and discrimination are widely recognized as barriers to accessing HIV prevention, treatment, care and support services. However, the negative effects of stigma and discrimination are particularly pertinent within the context of care and support programs for those infected and affected by HIV and AIDS in *non-clinical settings* (i.e., community settings). Hence, the Care and Support Consultation Group strongly endorsed the inclusion of an existing indicator with proven track record in the UNGASS indicator set. The proposed indicator is a recommended core indicator for national AIDS programs (see indicator #14 in *Guidance and*

Specifications for Additional Recommended Indicators. Core Indicators for National AIDS Programmes. Geneva: UNAIDS, 2008). These indicators -including the stigma indicator, are recommended for inclusion in national indicator sets in addition to the UNGASS indicators. They were selected and endorsed by a multi-stakeholder, consensus process and endorsed by the MERG. Their selection pre-dates the development and agreement on the MERG Indicator Standards. However, as provided in this document, the assessment of the stigma indicator according to the MERG Indicator Standards shows that this is a feasible and worthwhile indicator to collect and for which data is already available for a range of countries.

RECOMMENDATION 5.
EXPAND THE AGE RANGE FOR ALL UNGASS INDICATORS COLLECTED THROUGH POPULATION-BASED SURVEYS.
The age range in population-based surveys should be expanded to include older people up to 64 years old.

Rationale:

Seven of the current 25 core UNGASS indicators are monitored using data from population-based surveys, DHS and MICS. Of these, 3 indicators focus on adults' access to testing, multiple sexual partnerships, and condom use and are currently restricted to the 15-49 year age group. The same is true for some of the *Additional Recommended Indicators,* including the stigma indicator discussed above.

The age bracket commonly applied to DHS is 15-49. These age brackets were originally recommended because the majority of the DHS survey focused on issues of reproductive health and family planning. The DHS now includes topics of relevance to other age groups, including HIV and AIDS, female genital cutting, gender/domestic violence and women's empowerment, making the limited focus on those between the ages of 15 and 49 problematic. In 2006, UNAIDS recognized that 'the burden of disease extends beyond the age of 49' and stated that a 'substantial proportion of people living with HIV and AIDS were aged 50 years and older'. Older people are affected by HIV in two ways: (1) as people living with HIV; and, (2) as carers for others living with the virus and children orphaned or made vulnerable by AIDS. The reliance of UNGASS reporting on data from the DHS has led to a lack of understanding of the impact of HIV and AIDS on older people at both national and international levels, and a subsequent lack of attention to this group in the response.

In recent years, some DHS and other national population-based surveys have included people over the age of 49 and have provided particularly useful data. Hence, it has been demonstrated that it is feasible and worthwhile to extend the age bracket in these surveys. This would not disrupt trend data if data continued to be disaggregated by standard age groups for comparison with previous years. The Care and Support Consultation Group recommends the additional inclusion of 50-54, 55-59, and 60-64 year old age groups in order to gain a global understanding of the needs of older people in relation to HIV and AIDS and to what extent they have been addressed.

RECOMMENDATION 6.
DEVELOP MERG-ENDORSED, STANDARDIZED INDICATORS IN HIV/AIDS CARE AND SUPPORT FOR NATIONAL AIDS PROGRAMS.

Rationale:

An indicator identification, classification and standards-based analysis conducted in 2009, pointed to a large overall number of care and support indicators (220) but a very small number of indicators (7) which are *both* addressing critical components of comprehensive care and support in non-clinical settings *and* are of sufficient quality (as per MERG Indicator Standards) to be considered as viable indicators. In addition, not all of the limited number of indicators are intended for use at the national level from which indicators with a good track record can be selected for inclusion in the global UNGASS indicator set. Hence, the Care and Support Consultation Group was severely limited in its choice of appropriate existing indicators as enhanced or alternate indicators for inclusion in the UNGASS set. The general lack of standardized indicators in this programmatic area, was also confirmed by the web-based survey on current practices in national monitoring and by the analysis of indicators reported to the Global Fund as part of performance-based disbursement of grants.

The Care and Support Consultation Group, therefore, strongly recommends the development and pilot-testing of a concise set of standardized indicators for national AIDS programs which address the five essential components of comprehensive HIV/AIDS care and support and which adhere to the MERG Indicator Standards. The Group specifically notes the need for indicators in the following areas: (a) nutrition; (b) clinical care in non-clinical settings; (c) psychosocial support; (d) and care for caregivers.

1. UNGASS HIV/AIDS CARE AND SUPPORT CONSULTATION PROCESS

The consultation process was led by UNICEF and the Care and Support Working Group of the UK Consortium on AIDS and International Development (represented by VSO International and HelpAge International) and included the following key steps:

Step 1: Development and endorsement of Ground Rules and Terms of Reference to ensure a collaborative, transparent and standards-based process

The following *Ground Rules* were agreed by all stakeholders involved:
The UNGASS care and support indicator review process will be:

- *based on data use*: All proposed changes to the existing UNGASS indicators (i.e., indicator 2, 10 and 12) will be based on an explicit rationale for data use at the global and national levels.
- *standards-based*: All proposed changes to the existing UNGASS indicators (i.e., indicator 2, 10 and 11) will be based on an explicit rationale for adherence to the MERG indicator standards.
- *transparent:* The process for identifying relevant stakeholders and their roles and responsibilities in the review process will be made explicit.
- *consultative:* Broad input, feedback and endorsement will be sought based on the agreed review process and different stakeholder roles and responsibilities.
- *collaborative and product-focused:* A timeline for the different steps in the agreed process and the expectations for the final product will be made explicit. All stakeholders agree to participate in the review process in a manner conducive to achieving the end result.

The following *Terms of Reference* were agreed by all stakeholders involved:
Core team: representatives from UNICEF and the Care and Support Working Group of the UK Consortium on AIDS and International Development.
Priscilla Akwara (UNICEF), Rachel Yates (UNICEF), Rachel Albone (Helpage International), Mike Podmore (VSO International), Greet Peersman (consultant).
Responsibilities:

- Establish the process, criteria and mechanisms for the review process;
- Communicate with UNGASS Advisory Group and other UNGASS Consultation Groups (i.e., Prevention, Treatment, Enabling Environment);
- Conduct preparatory work for and lead all phases of the review process;
- Responsible for the content of the review product in accordance with the agreed criteria.

The specific responsibilities of the consultant included acting as an independent facilitator during the consultation process ensuring: (a) a consultative and collaborative process whereby input and feedback from all stakeholders was solicited and carefully considered; and, (b) transparency in decision-making through application of the agreed Standards and dissemination of the review results.

Stakeholder representatives: individuals acting as representatives of the broad care and support stakeholder group and able to provide an important contribution to the review process in terms of time commitment. They were selected based on: (a) experience with care and support programs and/or monitoring and evaluation (preferably in care and support and/or UNGASS reporting); *and*, (b) ensuring an appropriate mix of organizations (i.e., bi/multi-laterals, national governments, civil society including PLHIV, academia); *and*, (c) ensuring appropriate regional representation but with increased focus on East and Southern Africa (i.e., hyper endemics).

Responsibilities:
- Act as a representative of the wider stakeholder group;
- Participate in a workshop to recommend the most appropriate UNGASS indicator selection for care and support in accordance with agreed criteria;
- Provide key M&E technical and/or programmatic input in the review process for care and support indicators;
- Help problem-solve –as needed, any issues that come up throughout the review process.

Broad stakeholder group: those involved in care and support programs and interested in participating through an on-line survey.
Responsibility:
- Provide M&E technical/care and support programmatic input during specified feedback/endorsement periods.

Step 2: Definition of HIV/AIDS care and support based on current programmatic frameworks

The consultation was focused on HIV/AIDS care and support in *non-clinical settings* for adults and children infected/affected by HIV and AIDS, including orphans and vulnerable children. The Care and Support Consultation Group used current and endorsed care and support programmatic frameworks[1] to guide the consultation process. Based on these, HIV/AIDS care and support programs for adults and children (including orphans and vulnerable children) were defined as including the following critical components:

1. **Psychosocial component** including: counseling services, emotional and spiritual support (all part of palliative care); reduction of stigma and discrimination; positive living.
2. **Clinical component** including: testing; prevention of opportunistic infections, symptom control and pain management, treatment of AIDS-related illnesses and opportunistic infections including TB; and paediatric care (all part of palliative care); treatment adherence support and information; nutrition; alternative/traditional medicine.
3. **Social and economic component** including: social protection[2] (such as pensions, allowances, free or subsidized healthcare and school fees, child and disability benefits); targeted financial support (such as stipends, cash transfers, grants and help with funerals); income generation and employment opportunities; workplace policies and programs; capacity building and advocacy support; food and nutrition assistance and appropriate agricultural inputs and services; clean water; transport; positive prevention; education; orphan support; adoption services; help in the home and child care.
4. **Human rights and legal component** including: access to legal aid, legal support and accessible legal information; human rights legislation and implementation (including violence and discrimination; land, inheritance and property rights; labor laws); succession planning, rights-based approach and rights advocacy training.

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[1] *What do we really mean by 'care and support'. Progress towards a comprehensive definition, UK Consortium on AIDS and International Development, Care and Support Working Group, 2008* & *UNAIDS Outcome Framework Business Case Social Protection. Geneva: UNAIDS, 2010.*

[2] Social protection in the context of HIV is increasingly recognized as a strategy in the battle against HIV, and in particular towards the goal of universal access to prevention, treatment, care and support services. It includes all public and private initiatives that provide income or consumption transfers to the poor, protect the vulnerable against livelihood risks, and enhance the social status and rights of the marginalized with the overall objective of reducing their economic and social vulnerability (*UNAIDS Outcome Framework Business Case Social Protection. Geneva: UNAIDS, 2010).*

5. **Family & community component (more specifically defined as 'care for caregivers')** including: psychosocial (including bereavement support) and medical (all parts of palliative care); socio-economic and legal care and support (including prevention information).

Step 3: Identification of existing indicators in the area of HIV/AIDS care and support in non-clinical settings

In 2009, a review[3] was conducted of existing care and support indicators from seven organizations with substantive involvement in HIV/AIDS care and support (i.e., DFID, Early Childhood Development (ECD), Global Fund, PEPFAR, UNAIDS/UNGASS, World Bank, WHO) and from the UNAIDS Indicator Registry of HIV/AIDS indicators. The work included a classification of the indicators according to the five key components of a comprehensive care and support approach (see Step 2 above) and an assessment of these indicators according to the *MERG Indicator Standards*. The key findings were that of the 220 care and support indicators identified, the majority (40%) focused on clinical aspects; 18% on social and economic aspects; 16% on family and community aspects; 11% on psychosocial aspects; and, 8% on human rights/legal aspects. Some indicators did not have full specifications, hence it was difficult to assess their merit.

In preparation for the UNGASS care and support stakeholder workshop, relevant indicators (i.e., those within the scope of the consultation, see above) from these sources for which full indicator specifications are available, were selected for the short-list of indicators to consider as potential alternate or additional UNGASS indicators. Seven fully defined indicators were identified.

Step 4: ***Consultation with a broad stakeholder group through an on-line survey with the aim to identify current monitoring practices at the national level in the area of HIV/AIDS care and support.***

The on-line survey took place July-August 2010. This activity provided basic information about the range of indicators monitored at national level and the feasibility/challenges of data collection (see **Annex 1**). In addition, information was obtained from the Global Fund on the specific indicators reported within the context of performance-based disbursement of grants. While the Global Fund recommends standardized indicators (mostly harmonized with global partners) for monitoring and reporting on HIV/AIDS care and support programs, a wide variety of country-defined indicators was noted among the roughly 107 countries reporting. This poses considerable challenges in the aggregation of data across countries. Other challenges included: lack of survey data; lack of community-based data (compared to facility-based data); difficulties in determining indicator denominators; over-reporting/double-counting; unverifiable data records; and, low M&E capacity for data collection.

[3] Butler A, Drew R (August 2009). *Monitoring Care and Support Activities in Responses to HIV and AIDS. Review of Available Indicators.*

Step 5: Consultation with key stakeholder representatives through a 2-day workshop with the aim to select the most appropriate UNGASS indicators in the area of care and support in non-clinical settings in accordance with agreed criteria.

The stakeholder workshop took place in London (UK), 10-11 August 2010 (see **Annex 2**). Based on steps 3 and 4, draft standards-based assessments of existing UNGASS indicators and the potential additional/alternate indicators for inclusion in the UNGASS set were distributed to all participants in advance of the workshop and discussed and consolidated during the workshop. The discussions focused on the selection of indicators for which there is a proven track-record that they have high program relevance and that they are feasible to collect with reasonable cost and low data quality concerns. Consensus was reached on key recommendations for UNGASS care and support indicators and on follow-up work including liaison with other UNGASS consultation groups.

Step 6: Final round of input from key stakeholder representatives through sharing the workshop outputs.

A draft document with all consensus recommendations, the consolidated standards-based indicator assessments and the supporting rationale was distributed to all workshop participants for final comments. The content was subsequently revised and re-formatted according to the requirements for the submission document.

Step 7: Liaison with other UNGASS Consultation Groups

The following indicators were submitted to the Health Systems Consultation Group as they are 'out of scope' for care and support in *non-clinical settings* (i.e., both proposed indicators are collected at the health facility level), yet addressing critical issues in comprehensive care and support programs:

- Proportion of eligible adults and children living with HIV who received cotrimoxazole prophylaxis in a clinical setting during the reporting period
- Proportion of undernourished people living with HIV who received therapeutic or supplementary food during the reporting period

These indicators were ranked by the Health Systems Consultation Group as *low priority* compared to a range of other existing and/or newly proposed UNGASS indicators within the scope of this Consultation Group.

The recommendations on NCPI questions relevant to care and support in non-clinical settings and the stigma indicator (i.e., the proposed new UNGASS indicator) were submitted for feed-back to the Enabling Environment Consultation Group.

(a) *Feedback received on NCPI recommendations*: The full *draft* NCPI with track changes (i.e., version not yet finalized for submission by the Enabling Environment Group) was shared on 26 Sept. The Care and Support Group noted that some of its key recommendations were not included, yet a standards-based rationale for these decisions was not provided. More detailed comments are provided on p.31-34.

(b) Feedback received on the stigma indicator (verbatim, e-mail received from Brian Lutz on 23 Sept): *"As we understand stigma to be part of what is meant by 'enabling environment', one of our Expert groups looked carefully at the possible inclusion of a stigma indicator in the core set of quantitative UNGASS indicators. Their work leveraged a much larger process – jointly led by the Global Network of People Living with HIV (GNP+), International Center for Research on Women (ICRW), International Planned Parenthood Federation (IPPF) and UNAIDS – that has been exploring this issue for some time.*

Based on this and other work, we very much agree with your team that addressing stigma is a critically important part of a country's AIDS response and, if an appropriate indicator can be developed, included as part of UNGASS monitoring. At this time, however, we concluded that neither an existing nor newly proposed stigma indicator was ready for inclusion in the UNGASS indicator set. There was consensus that existing indicators did not capture and measure stigma sufficiently well and that newer, and potentially promising indicators, have not necessarily received the full validation and field-testing required to be acceptable by the MERG. Among the indicators considered by our Expert group was 'Accepting Attitudes Toward People Living with HIV.' It was noted that field-testing of this indicator yielded some weaknesses in its validity and that DHS may replace this indicator once the MERG accepts a new one. Consequently, the Enabling Environment consultation group's perspective is that while stigma should be tracked in the UNGASS set, we recommend waiting for the next round of revisions to the UNGASS indicators to ensure that the most appropriate and rigorously field-tested stigma indicator is selected."

Note: In reply, the Care and Support Group requested the specific standards-based concerns from the Enabling Environment Group. A written reply was not received before the UNGASS submission deadline of 28 September 2010. Although subsequently agreed at the UNGASS meeting (5-6 Oct 2010) with all Consultation Groups, no further information was provided in writing to the Care and Support Core Team before this document was re-submitted on 11 October 2010.

Based on its strict adherence to a transparent and standard-based process for decision-making regarding UNGASS indicators, the Care and Support Group recommends the following:

(a) *NCPI:* All recommendations from the Care and Support Consultation (as per included in this document) should be maintained in the final version of the NCPI as they are supported by a favorable standard-based assessment and compliment the limited number of quantitative UNGASS indicators (i.e., 3) proposed for care and support in non-clinical settings.

(b) *Stigma indicator:* While the Care and Support Group agrees with the need for a stronger stigma measure, yet to be developed and pilot-tested according to MERG Standards, the Group recommends the inclusion of the existing stigma indicator as its standards-based assessment has an overall high score, standardized data collection tools are in place and will continue to be used to collect this indicator, and data is already available from a range of countries as a basis of much needed trend analysis. As indicated above, this indicator was also approved through a multi-agency process and through the MERG in 2008 as part of the 'Additional Recommended Indicators'.

Step 8: Sharing information on the UNGASS care and support review process and on its outputs to maximize transparency and buy-in. The final submission document is shared on a dedicated webpage hosted on the UK Consortium on AIDS and International Development (http://www.aidsconsortium.org.uk/UNGASS Consultation.htm).

2. PROPOSED UNGASS INDICATORS IN HIV/AIDS CARE AND SUPPORT IN NON-CLINICAL SETTINGS

2.1 Objectives of the HIV/AIDS care and support indicator consultation

Using the agreed Standards:
1. assess whether the existing indicators (a) adequately cover the critical issues for which regularly reported data are required; and (b) are defined in such a way as to provide high quality, directly comparable, data;
2. determine necessary changes of the existing indicator set including: (a) revision or removal of existing indicators; and/or, (b) addition of new indicators.

It was agreed that:
(a) to minimize the negative implications of changes in the existing UNGASS care and support indicators[4], changes should only be recommended if a clear rationale is provided based on significant challenges identified in the Standards-based assessment;
(b) to minimize the data collection and reporting burden, maximum 4 quantitative indicators should be recommended to monitor progress in the area of care and support in non-clinical settings and a concise number of questions collected through the NCPI;
(c) the comprehensive definition of care and support (addressing the five essential programmatic components) should be used to select the indicators.

[4] *Implications for quantitative indicators:* trend data is disrupted; data collection methods (such as population-based surveys and/or country program monitoring systems) may need to be adjusted; data use products may need to be adjusted; country partners may need to be re-trained in how to collect and/or use the indicators.
Implications for the NCPI: If questions are deleted or substantially rephrased: the 'logical framework' of the NCPI may be affected and trend data is disrupted. If questions are added: the questionnaire may become more complex and take longer to complete.

2.2 Summary of the consultation results

The below table provides an overview of the existing, in-scope and fully defined indicators which were considered in the standards-based consultation process for modification of existing UNGASS indicators or alternate/additional UNGASS indicators.

Indicators in HIV/AIDS care and support in non-clinical settings			
Existing UNGASS indicators	**'Additional Recommended' indicators***	**Global Partner indicators** [source indicated]	**Recommended modification**
Indicator 10. Percentage of orphans and vulnerable children whose households received free basic external support in caring for the child	N/A	Percentage of orphaned and vulnerable children aged 5–17 years who have three basic material needs met [source: OVC indicator manual; Global Fund]	Proportion of eligible households who received economic support in the last 3 months
		Number of eligible adults and children provided with minimum of one care service [source: PEPFAR]	
		Number of adults and children living with HIV who receive care and support services outside facilities during the reporting period [source: Global Fund]	
UNGASS indicator 12. Current school attendance among orphans and among non-orphans (10-14 year olds)	N/A	N/A	Expand age groups: Current school attendance among orphans and among non-orphans (10-14 year olds, primary school age, lower secondary school age)
UNGASS indicator 2. National Composite Policy Index (sub-set of relevant questions)	N/A	N/A	Minor modifications only [see track changes on pages 31-34 and Annex 4]

	Indicator #14: Percentage of women and men aged 15-64 expressing accepting attitudes towards people living with HIV		Include in UNGASS indicator set and expand age groups
N/A		Ratio of OVC versus non-OVC aged 12-17 with an adequate score for psychological health [source: OVC indicator manual]	Based on the standards-based assessment of each of these indicators, they were considered *not* to be viable additions/alternatives for inclusion in the UNGASS indicator set
N/A		Ratio of food insecure households with OVC compared to households without OVC [source: OVC indicator manual]	
N/A		Number of eligible clients who received food and/or nutrition services [source: PEPFAR]	
Other crucial areas of care and support			
N/A	N/A	Percentage of facilities that provide comprehensive care referrals for HIV/AIDS care and support services when these services are not available on site [source: WHO]	Based on the standards-based assessment of this indicator, it was considered *not* to be a viable addition/alternative for inclusion in the UNGASS indicator set
		Proportion of eligible adults and children living with HIV who received cotrimoxazole prophylaxis in a clinical setting during the reporting period [source: PEPFAR]	The Care and Support Consultation Group deemed both areas important for indicator development but as these fell outside the scope of the Care and Support Consultation Group, they were referred to the Health Systems Consultation Group as indicators to be measured in clinical settings. See recommendations by the Health Systems Consultation Group
		Proportion of undernourished people living with HIV who received therapeutic or supplementary food during the reporting period [source: PEPFAR]	

***** see *Guidance and Specifications for Additional Recommended Indicators. Core Indicators for National AIDS Programmes. Geneva: UNAIDS, 2008*

2.3 Detailed indicator specifications and MERG standards-based assessments

2.3.1 Modified UNGASS indicator 10. Proportion of eligible households who received economic support in the last 3 months

RECOMMENDATION: ***The existing UNGASS Indicator 10. "Percentage of orphans and vulnerable children whose households received free basic external support in caring for the child" should be modified to "Proportion of eligible households who received economic support in the last 3 months".***

Rationale:

UNGASS indicator 10[5] was measured through population-based surveys such as DHS, AIS and MICS. Questions to construct this indicator were recently removed from these surveys due to the following key challenges: (a) measuring 'external support' according to the broad definition included in the indicator, required a large number of survey questions and thus substantial interview time; (b) interpretation of the data in terms of support for households affected by HIV and AIDS was difficult; and (c) using proxies of AIDS affectedness such as chronic illness in households have generally been difficult, as the links to HIV and AIDS have often been weak, as are associations between chronic illness and poor developmental outcomes. However, there is still a critical need to measure progress in care and support services directed to the household level as substantial resources continue to be invested in these services, and thus a measure of coverage is essential. The modified indicator also reflects the growing international commitment to HIV-sensitive social protection as reflected in the UNAIDS Outcome Framework (UNAIDS 2010) and Business Case on Social Protection (UNAIDS 2010) and supports the growing evidence on the effect of economic support as a key strategy in combating HIV and AIDS. Tracking coverage of support for orphans and children within poor households remains a developmental priority as reflected in the strategic plans of countries and of organizations such as UNAIDS, UNICEF, and PEPFAR. The modified indicator overcomes the data collection and interpretation challenges of the existing UNGASS indicator 10. It is of programmatic relevance mostly to countries with high HIV prevalence and to a range of international organizations/donor agencies; hence, it supports the global indicator harmonization agenda.

This modification to UNGASS indicator 10 is proposed in recognition of the continuing need to measure support for households, including adults and children affected by HIV and AIDS. The specific difficulties in collecting and interpreting the existing UNGASS indicator 10 are overcome in this modified indicator by: (a) focusing the denominator on poverty-related determinants of vulnerability (based on evidence from recent vulnerability analyses[6]); and, (b) narrowing the broad definition of 'external support' to economic support (with a focus on social assistance and livelihoods assistance) to poor and HIV-affected households which remains a high priority in many care and support activities.[7]

It is recognized that in many cases, family, friends or neighbors provide substantial economic support to needy households (for example, through remittances), and thus, it is important to capture such support along with economic support provided by civil society organizations and/or government. However, in

[5] See **Annex 3** for the detailed indicator specifications and MERG Standards-based assessment.
[6] Akwara et al. 2010. Who is the vulnerable child?
[7] At the stakeholder meeting it was recognized that economic support is necessary but not sufficient for households affected by HIV and AIDS, and this in the longer term, more work is needed to develop indicators to capture access to social care including psychosocial support (see recommendation 6).

order to keep measurement as simple as possible, the indicator does not attempt to identify the different sources of support to households (there is an opportunity to partly capture this information at country level in National AIDS Spending Assessments, NASA).

The modified indicator also reflects the growing international commitment to and evidence for the effectiveness of HIV-sensitive social protection as reflected in the UNAIDS Outcome Framework (UNAIDS 2010) and Business Case on Social Protection (UNAIDS 2010). There is recognition that the household should be the primary unit of analysis since many of the care and support services are directed to the household level. However, household data should be disaggregated to track the number of children, including orphans, as well as adults receiving support. Tracking coverage of support for orphans and children within poor households remains a developmental priority as reflected in country and organizational strategic plans (e.g., UNAIDS, UNICEF, PEPFAR).

A. REQUESTED INDICATOR INFORMATION for *modified UNGASS indicator 10: Proportion of eligible households who received economic support in the last 3 months*

Note: The following full indicator description is provided according to the format currently used in the UNGASS Guidelines.

TITLE: Economic support for eligible households

Economic support (with a focus on social assistance and livelihoods assistance) to poor and HIV-affected households remains a high priority in many comprehensive care and support programs. This indicator reflects the growing international commitment to HIV-sensitive social protection. It recognizes that the household should be the primary unit of analysis since many of the care and support services are directed to the household level. However, household data should be disaggregated to track the number of children, including orphans, as well as adults receiving support. Tracking coverage of support for orphans and children within poor households remains a developmental priority.

Numerator: Number of eligible households that received any form of economic support in the last 3 months
Denominator: Total number of eligible households

An eligible household is defined as a household in the bottom wealth quintile.

Countries should use the exact indicator definition and method of measurement for standardized progress monitoring and reporting at national and global levels. This will allow monitoring of changes over time and comparisons across different countries. However, countries can add or exclude other categories locally (for example, other wealth quintiles) depending on the country needs with respect to national program planning and implementation.

PURPOSE
To assess progress in providing economic support to poor and other eligible households affected by HIV and AIDS

APPLICABILITY
Mainly high HIV prevalence contexts

DATA COLLECTION FREQUENCY
Every 3 to 5 years

MEASUREMENT TOOL
Population-based surveys such as Demographic Health Survey, AIDS Indicator Survey, Multiple Indicator Cluster Survey or other nationally representative surveys.

METHOD OF MEASUREMENT
As part of a household survey, a household roster should be used to list all members of the household together with their ages, and identify all households with children less than 18 years of age, and with orphans, in the last year before the survey. Questions are then asked for each such household about the types of economic support received in the last 3 months, and the primary source of the help.

The household heads or respondents are asked the following questions about the type of economic support they have received in the last 3 months.

Has your household received any of the following forms of economic support in the last 3 months:

a) Cash transfer (e.g., pensions, disability grant, child grant)

b) Assistance for school fees

c) Material support for education (e.g., uniforms, school books etc)

d) Income generation support in cash or kind e.g. agricultural inputs

e) Food assistance provided at the household or external institution (e.g., at school)

f) Material or financial support for shelter

g) Other form of economic support (including remittances)

An assessment of the households wealth (through an assessment of asset ownership) is completed at the data analysis stage using the wealth quintile at which point it will possible to assess the extent to which poorest households are receiving external support[8].

Disaggregation of data
It is recommended that the indicator is disaggregated by type of economic support in order to track the different types of economic support provided - particularly

[8] In Mozambique, for example, analysis of access by poor households to cash transfers has been done through building an asset/wealth index using a national household survey, which calculated the quintiles cut-off points.

to be able to distinguish between access to free social assistance such as cash transfers (often targeted at poor labour-constrained households) and livelihoods support which is often targeted at poor households which are less labour-constrained.

It is also recommended that the indicator is disaggregated by orphanhood status as orphaning remains a major determinant of vulnerability, particularly in relation to access to services.

Where possible, data should also be disaggregated by sex, age and rural versus urban residence.

For countries which opt to add data collection on households in other wealth quintiles in addition to those in the bottom quintile, the indicator can also be disaggregated by wealth quintile to track external support reaching the bottom quintile compared to wealthier quintiles.

INTERPRETATION

This indicator reflects new evidence of the need for a greater focus on wealth dimensions of vulnerability and the fact that that targeting on the basis of extreme poverty in high prevalence contexts ensures good coverage of poor households affected by HIV and AIDS [9]. Proxy indicators of AIDS affectedness (such as "chronic illness') have often been poorly associated with HIV, have weak associations with adverse developmental outcomes, and have proven difficult to define in household questionnaires.

The indicator will demonstrate changing levels of economic support for poorest households. In high prevalence contexts, in particular, the majority are likely to be HIV affected. The indicator will also demonstrate changes in the composition of external support (e.g. cash, food, livelihoods) received by poor households.

The indicator does not measure directly economic support to HIV infected and affected households, which is difficult to establish during a survey, but implicitly suggests that households living in the bottom wealth quintile in high prevalence contexts are more likely to be negatively impacted by HIV and AIDS and in need of economic assistance.

It is recognized that in many cases, family, friends or neighbours provide substantial economic support to needy households (e.g., through remittances) and thus, it is important to capture such support along with economic support provided by civil society organizations and/or government. However, in order to keep measurement as simple as possible, the indicator does not attempt to identify the different **sources** of support to households but this should be partly captured in National AIDS Spending Assessments (NASA).

The collection of data through population-based surveys, particularly DHS and MICS, means that the indicator does not capture the status of people living outside of households such as street children, children in institutions and internally displaced populations. Separate surveys are needed to track coverage for such vulnerable populations.

[9] Evidence from social assistance programmes in Malawi and Zambia the effectiveness of using vulnerability criteria without specific reference to AIDS to target children and families affected by AIDS. These programmes target the ultra poor and labour constrained and in using these criteria researchers found that 80% of all households directly affected by HIV and AIDS that are ultira poor and labour constrained were reached. (UNICEF 2007).

B. MERG INDICATOR STANDARDS ASSESSMENT

1. Is the indicator fully described?

MERG Indicator Standards [MERG Indicator Standard 3] **Assessment Result: 14/14**

- *Title and definition (max 2 points):* ***2***
- *Purpose and rationale (max 2 points):* ***2***
- *Method of measurement (max 4 points):* ***4***
- *Collection method (max 1 point):* ***1***
- *Measurement frequency (max 1 point):* ***1***
- *Details of any disaggregation (max 1 point):* ***1***
- *Guidelines on how to interpret changes in the indicator (max 1 point):* ***1***
- *Strengths and weaknesses of the indicator (max 1 point):* ***1***
- *Additional sources of information (max 1 point):* ***1***

Maximum 14 points

Conclusion: The indicator has a high score for this Standard. It should, therefore, allow for standardized data collection and directly comparable data across countries and over time.

2. How will the data from this indicator be used?

Data will be used to monitor global progress in providing economic strengthening to the poorest households in high prevalence countries, where a large proportion of the population is AIDS-affected. It will demonstrate both progress and gaps in the international care and support response and provide data for programming and advocacy purposes. It is also a key indicator for organizations working on care and support to be able to demonstrate impact of programming and attract continuing funding for a neglected area of the HIV response.

MERG Indicator Standards [MERG Indicator Standard 1] **Assessment Result: 10/11**

- *This indicator measures performance against a key international commitment, for example, MDGs, UNGASS (max 1 point):* ***0*** *[not currently part of an international agreement, but there is increased commitment from a range of international agencies/donors and increasing evidence to support this type of indicator]*
- *This indicator is relevant to some/all country contexts (max 1 point):* ***1*** *[though for HIV-affected households, mostly in high prevalence contexts]*
- *This indicator produces information which is needed by and useful to in-country stakeholders (max 1 point):* ***1***
- *Information from this indicator would be helpful/essential at global/international level to distinguish performance of different countries in responding to HIV and AIDS (max 2 points):* ***2***

- *Information from this indicator would be helpful/essential for those managing national responses to HIV and AIDS (max 2 points):* ***2***
- *Information from this indicator is helpful/essential at global/international level to allow decisions to be made in terms of programme development and resource allocation (max 2 points):* ***2***
- *Information from this indicator is helpful/essential at national level to allow decisions to be made in terms of programme development and resource allocation (max 2 points):* ***2***

Maximum 11 points

Conclusion: The indicator has a high score for this Standard. As there is growing evidence and commitment for economic support as a key strategy to combat the HIV epidemic and addressing overall vulnerability of households, this indicator has high programmatic relevance at both national and global levels.

3. What steps have been taken to ensure the indicator is harmonised with other indicators?

Collecting data will be done through MICS and DHS and therefore will not require any parallel data collection processes. As there are a dearth of global indicators on care and support and social protection this indicator will not duplicate other global indicators and indeed is an important addition to the global data set.

MERG Indicator Standards [MERG Indicator Standard 1] **Assessment Result: 2/5**

- *This indicator is accepted and used by all major international partners working in this technical area (max 1 point):* ***0***
- *This information is not available from other indicators (max 1 point):* ***1***
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding detailed description (max 1 point):* ***0***
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding systems for data collection (max 1 point):* ***0***
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding time frames for data collection (max 1 point):* ***1***

Maximum 5 points

Conclusion: The indicator has a low score for this Standard. It should be noted that issues of harmonization are currently low as this is a newly modified indicator and thus harmonization processes still need to be undertaken. However, given the increased international commitment to and the inclusion of economic support in country and organizational strategic plans, the prospects for harmonization success are good.

4. What process has been followed to ensure the technical value of this indicator?

The modification of this indicator has drawn on new vulnerability analysis which shows the importance of using wealth status in determining the most vulnerable households. The same analysis highlights some of the deficiencies in various AIDS related proxies such as chronic illness. The indicator draws on programmatic evidence, e.g. Malawi and Zambia showing how targeting of ultra-poor households is effective for reaching vulnerable AIDS affected households. The indicator is based on consultations with specialists working on both HIV/AIDS and social protection and draws on evidence from civil society, donors and UN agencies regarding the main areas of economic support being provided to households. Finally, the indicator has been discussed with specialists working on MICS and DHS

household surveys. The indicator has been discussed with specialists mainly in southern Africa and Latin America.

MERG Indicator Standards [MERG Indicator Standard 2] **Assessment Result: 8/9**

- *The indicator is significant and important within a particular technical field (max 1 point):* ***1***
- *The indicator provides a clear and focused measure of progress in a particular technical area (max 1 point):* ***1***
- *There is a clear understanding of what changes in the value of the indicator mean, how they should be interpreted and what kind of action to take as a result (max 1 point):* ***1***
- *The indicator is sensitive to pick up small changes in performance (max 1 point):* ***1***
- *The indicator is reliable and sensitive (max 1 point):* ***1***
- *The indicator is valid and specific (max 1 point):* ***1***
- *The indicator has previously been reviewed by people with expertise in the relevant technical area (max 1 point):* ***1***
- *The indicator has previously been reviewed by people with monitoring and evaluation expertise, including particularly indicator design (max 1 point):* ***1***
- *The indicator has previously been reviewed by people with experience in a wide range of countries with different types of HIV epidemics (max 1 point):* ***0***

Maximum 9 points

Conclusion: The indicator has a high score for this Standard. If deemed necessary, a quick review by selected people in countries (to ameliorate the last item on the Standard) can be achieved within the timeline of the current UNGASS review process.

5. What evidence is there that it will be feasible to track this indicator?

MERG Indicator Standards [MERG Indicator Standard 4] **Assessment Result: 8/12**

- *The number of countries in which systems and mechanisms needed to collect data for this indicator are functioning (max 3 points):* ***2***
- *The number of countries in which systems and mechanisms needed to interpret and use data for this indicator are functioning (max 3 points):* ***3***
- *The number of countries in which this indicator is already included in national AIDS M&E systems (max 3 points):* ***0***
- *Evidence is presented that financial and human resources are available to measure this indicator (max 2 points):* ***2***
- *Evidence is presented that measuring this indicator is worth the cost (max 1 point):* ***1***

Maximum 12 points

Conclusion: The indicator has a high score for this Standard. Given the programmatic significance of this modified indicator, it should be re-introduced in DHS, AIS and MICS surveys. Hence, the scoring for this Standard is supported by evidence of feasibility and cost-effectiveness of the indicator collection given that these surveys are regularly implemented and contain other UNGASS indicators. As with all indicator data, continued support to countries for integrated data analysis and interpretation is needed. Similar indicators have already been collected through population-based surveys in select countries, mostly in Latin America and Africa (e.g., Chile, Brazil and Mozambique) and elements of economic support were also included previously in DHS, AIS and MICS (i.e., as part of the broader definition of 'external support' in UNGASS indicator 10). The denominator reflects a standard and routinely used variable in key surveys.

Estimates of the systems required: no additional requirements as the indicator is to be incorporated in standard survey instruments used for collecting other relevant UNGASS and national indicator data.
Estimates of the resources required: no additional requirements.

6. Where is the indicator currently being used? Where has it been field-tested?

MERG Indicator Standards [MERG Indicator Standard 5] **Assessment Result: 2/7**

- *The number of countries in which the indicator has been field-tested or used operationally*
  - *Country's national program (max 3 points): **1***
  - *Countries with similar epidemics (max 2 points): **0***
  - *Other countries (max 1 point): **0***
- *This indicator is/will be part of a global system of periodic review (max 1 point): **1***

Maximum 7 points

Conclusion: The indicator has a low score for this Standard. This is an under-estimate of the numerator performance as similar indicators have already been collected through population-based surveys in select countries, mostly in Latin America and Africa (e.g., Chile, Brazil and Mozambique) and elements of economic support were also included previously in DHS, AIS and MICS (i.e., as part of the broader definition of 'external support' in UNGASS indicator 10). In that sense, this indicator has been operationally used. However, the most relevant experience is recent and has been outside of the HIV and AIDS context (for example, to measure coverage of cash transfers) and with slightly different definition of economic support items. The denominator reflects a standard and routinely used variable in key surveys.

Summary results
The modified indicator overcomes the key challenges identified for the existing UNGASS indicator 10. It addresses an important international commitment but evidence of use is currently limited as similar measures have only been introduced recently in population-based surveys outside of the HIV and AIDS context.

Overall score: 44/58 (76%)

Key strengths:
- programmatic relevance: Yes
- essential for decision-making: Yes
- quality concerns are low: Yes

Key weaknesses:
- high reporting rate: No
- existing trend data: No

2.3.2 Existing UNGASS indicator 12. Current school attendance among orphans and among non-orphans (10–14 year olds, primary school age, lower secondary school age)

RECOMMENDATION: This UNGASS indicator should be continued to be measured as per its current specifications but with an expansion in age groups. In addition to 10-14 year olds, data should also be included on orphans/non-orphans of primary school age and lower secondary school age. The following issue for potential indicator improvement should be considered for the next UNGASS indicator revision round: the global significance and data collection feasibility of a measure of 'school attendance' that extends beyond the current 'attend school *at any time* during the school year'.

Rationale:

Based on analyses of recent indicator data for a range of countries, UNGASS indicator 12 continues to be a sensitive measure for identifying disparities between orphans/non-orphans. This is also a Millennium Development Goals (MDG) indicator. Hence, continued measurement of this indicator –without modification, is worthwhile, feasible (i.e., using existing data collection tools) and allows for much needed trend data linked to both UNGASS and MDG commitments. However, an expansion in age groups is recommended. In addition to 10-14 year olds, data should also be included on orphans/non-orphans of primary school age and lower secondary school age. The current age range (10-14 year olds) cannot be correlated to primary school age or to lower secondary school age which makes it difficult to work with in educational settings. In addition, attendance rates often show a sharp decline from primary to secondary school (especially when primary school education is compulsory); hence, the children currently included in the numerator and in the denominator are subject to different attendance prevalence.

In addition, the proposed investigation for indicator improvement needs to address the following issue: the current measurement of 'school attendance' is a poor proxy for what can be considered 'adequate' attendance; however, a 'minimum required attendance' would need to be agreed (often this is considered to be not less than 80% of class time) and the feasibility of such a measure as a 'standardized global indicator' for which it is feasible to collect good quality data needs to be carefully considered. This is considered of utmost importance, but a multi-stakeholder, standards-based, consensus process for identifying an existing indicator with proven track record or for developing and pilot-testing a new indicator cannot be completed within the time line of the current UNGASS indicator review. The modified or new indicator also needs to be in line with the new MDG which are currently under review.

A. REQUESTED INDICATOR INFORMATION for *existing UNGASS indicator 12. Current school attendance among orphans and among non-orphans(10-14 year olds, primary school age, lower secondary school age)* [Note: age groups expansion]

Note: The following full indicator description is provided according to the format currently used in the UNGASS Guidelines (*United Nations General Assembly Special Session on HIV/AIDS. Monitoring the Declaration of Commitment on HIV/AIDS. Guidelines on Construction of core indicators. 2010 Reporting. Geneva: UNAIDS 2009).* [http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2009/20090331_UNGASS2010.asp] (p.50-51)).

TITLE: Orphans: School attendance

AIDS is claiming an ever growing numbers of adults just at the time in their lives when they are forming families and bringing up children. As a result, orphan prevalence is rising steadily in many countries, while fewer relatives within the prime adult ages mean that orphaned children face an increasingly uncertain future. Orphanhood is frequently accompanied by prejudice and increased poverty, factors that can further jeopardize children's chances of completing school education and may lead to the adoption of survival strategies that increase vulnerability to HIV. It is important therefore to monitor the extent to which AIDS support programmes succeed in securing the educational opportunities of orphaned children.

PURPOSE
To assess progress towards preventing relative disadvantage in school attendance among orphans versus non-orphans

APPLICABILITY
All countries

DATA COLLECTION FREQUENCY
Preferred: Every two years
Minimum: every 4 to 5 years

MEASUREMENT TOOL
Population-based survey (Demographic Health Survey, AIDS Indicator Survey, Multiple Indicator Cluster Survey or other representative survey)

METHOD OF MEASUREMENT
For every child aged 10–14, primary school age, lower secondary school age living in a household, a household member is asked: [Note: age groups expansion].
1. Is this child's natural mother still alive? If yes, does she live in the household?
2. Is this child's natural father still alive? If yes, does he live in the household?
3. Did this child attend school at any time during the school year?

Part A: Current school attendance rate of orphans aged 10–14, primary school age, lower secondary school age [Note: age groups expansion].
Numerator: Number of children who have lost both parents and who attend school
Denominator: Number of children who have lost both parents

Part B: Current school attendance rate of children aged 10–14, primary school age, lower secondary school age both of whose parents are alive and who live with at least one parent [Note: age groups expansion].
Numerator: Number of children both of whose parents are alive, who are living with at least one parent and who attend school
Denominator: Number of children both of whose parents are alive who are living with at least one parent

This indicator should be reported disaggregated by sex and by age (10-14 year olds, primary school age, lower secondary school age). [Note: age groups expansion].

INTERPRETATION
The definition of orphan/non-orphan used here—i.e., child aged 10–14 years as of the last birthday both of whose parents have died/are still alive—is chosen so that the maximum effect of disadvantage resulting from orphanhood can be identified and tracked over time. The age-range 10–14 years is used because younger orphans are more likely to have lost their parents recently so any detrimental effect on their education will have had little time to materialize. However, orphaned children are typically older than non-orphaned children (because the parents of younger children have often been HIV-infected for less time) and older children are more likely to have left school. The additional age groups (orphans/non-orphans of primary school age and lower secondary school age) are included to be able to correlate more easily with typical educational settings. Attendance rates often show a sharp decline from primary to secondary school (especially when primary school education is compulsory); hence, it is important to track these specific age groups.
Typically, the data used to measure this indicator are taken from household-based surveys. Children not recorded in such surveys—e.g., those living in institutions or on the street—generally, are more disadvantaged and are more likely to be orphans. Thus, the indicator will tend to understate the relative disadvantage in educational attendance experienced by orphaned children.
This indicator does not distinguish children who lost their parents due to AIDS from those whose parents died of other causes. In countries with smaller epidemics or in the early stages of epidemics, most orphans will have lost their parents due to non-HIV-related causes. Any differences in the treatment of orphans according to the known or suspected cause of death of their parents could influence trends in the indicator. However, to date there is little evidence that such differences in treatment are common.
The indicator provides no information on actual numbers of orphaned children. The restrictions to double orphans and to the specific age groups mean that estimates may be based on small numbers in countries with small or nascent epidemics.

FURTHER INFORMATION
For further information, please consult the following website: http://www.unicef.org/aids/index_documents.html

B. MERG INDICATOR STANDARDS ASSESSMENT

1. Is the indicator fully described?

MERG Indicator Standards [MERG Indicator Standard 3] **Assessment Result: 14/14**

- *Title and definition (max 2 points):* ***2***
- *Purpose and rationale (max 2 points):* ***2***
- *Method of measurement (max 4 points):* ***4***
- *Collection method (max 1 point):* ***1***
- *Measurement frequency (max 1 point):* ***1***
- *Details of any disaggregation (max 1 point)* ***1****:*
- *Guidelines on how to interpret changes in the indicator (max 1 point):* ***1***
- *Strengths and weaknesses of the indicator (max 1 point):* ***1***
- *Additional sources of information (max 1 point):* ***1***

Maximum 14 points

Conclusion: The indicator has a high score for this Standard. It should, therefore, allow for *continued* standardized data collection and directly comparable data across countries and over time.

2. How will the data from this indicator be used?

MERG Indicator Standards [MERG Indicator Standard 1] **Assessment Result: 11/11**

- *This indicator measures performance against a key international commitment, for example, MDGs, UNGASS (max 1 point):* ***1***
- *This indicator is relevant to some/all country contexts (max 1 point):* ***1***
- *This indicator produces information which is needed by and useful to in-country stakeholders (max 1 point):* ***1***
- *Information from this indicator would be helpful/essential at global/international level to distinguish performance of different countries in responding to HIV and AIDS (max 2 points):* ***2***
- *Information from this indicator would be helpful/essential for those managing national responses to HIV and AIDS (max 2 points):* ***2***
- *Information from this indicator is helpful/essential at global/international level to allow decisions to be made in terms of programme development and resource allocation (max 2 points):* ***2***
- *Information from this indicator is helpful/essential at national level to allow decisions to be made in terms of programme development and resource allocation (max 2 points):* ***2***

Maximum 11 points

Conclusion: The indicator has a high score for this Standard. Therefore, it continues to have high programmatic relevance and use.

3. What steps have been taken to ensure the indicator is harmonised with other indicators?

MERG Indicator Standards [MERG Indicator Standard 1] **Assessment Result: 4/5**

- *This indicator is accepted and used by all major international partners working in this technical area (max 1 point):* ***1***
- *This information is not available from other indicators (max 1 point):* ***1***
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding detailed description (max 1 point):* ***extent not known***
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding systems for data collection (max 1 point):* ***1***
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding time frames for data collection (max 1 point):* ***1***

Maximum 5 points

Conclusion: The indicator has a medium score for this Standard. The extent of full harmonizaton *across* the eduacation and HIV/AIDS field is not known, but there are no 'other similar' (and thus non-harmonized) indicators *within* the HIV/AIDS-specific field.

4. What process has been followed to ensure the technical value of this indicator?

MERG Indicator Standards [MERG Indicator Standard 2] **Assessment Result: 9/9**

- *The indicator is significant and important within a particular technical field (max 1 point):* ***1***
- *The indicator provides a clear and focused measure of progress in a particular technical area (max 1 point):* ***1***
- *There is a clear understanding of what changes in the value of the indicator mean, how they should be interpreted and what kind of action to take as a result (max 1 point):* ***1***
- *The indicator is sensitive to pick up small changes in performance (max 1 point):* ***1***
- *The indicator is reliable and sensitive (max 1 point):* ***1***
- *The indicator is valid and specific (max 1 point):* ***1***
- *The indicator has previously been reviewed by people with expertise in the relevant technical area (max 1 point):* ***1***
- *The indicator has previously been reviewed by people with monitoring and evaluation expertise, including particularly indicator design (max 1 point):* ***1***
- *The indicator has previously been reviewed by people with experience in a wide range of countries with different types of HIV epidemics (max 1 point):* ***1***

Maximum 9 points

Conclusion: The indicator has a high score for this Standard. Hence, it will continue to provide good quality data from DHS, AIS and MICS.

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5. What evidence is there that it will be feasible to track this indicator?

MERG Indicator Standards [MERG Indicator Standard 4] **Assessment Result: 12/12**

- *The number of countries in which systems and mechanisms needed to collect data for this indicator are functioning (max 3 points): **3***
- *The number of countries in which systems and mechanisms needed to interpret and use data for this indicator are functioning (max 3 points):**3***
- *The number of countries in which this indicator is already included in national AIDS M&E systems (max 3 points): **3***
- *Evidence is presented that financial and human resources are available to measure this indicator (max 2 points): **3***
- *Evidence is presented that measuring this indicator is worth the cost (max 1 point): **1***

Maximum 12 points

Conclusion: The indicator has a high score for this Standard.
Estimates of the systems required: no additional requirements as the indicator is already incorporated in standard survey instruments used for collecting other relevant UNGASS and national indicator data.
Estimates of the resources required: no additional requirements.

6. Where is the indicator currently being used? Where has it been field-tested?

UNGASS data availability: # countries reporting:
2004: Generalized epi: 47
Low/Concentrated epi: N/A
2006: 59 countries
2008: 90 countries
2010: 45 countries
[Note: Data across reporting periods may overlap as surveys are conducted every 3-5 years only]

Additional information on data availability from *Progress report for children affected by HIV/AIDS, UNICEF, December 2009*:
countries reporting: 49 (representing 37% of global population)
Time period: DHS, HMIS and MICS conducted in 2002 or later
countries with two or more measurements: 34

MERG Indicator Standards [MERG Indicator Standard 5] **Assessment Result: 7/7**

- *The number of countries in which the indicator has been field-tested or used operationally*
  - *Country's national program (max 3 points): **3***

- *Countries with similar epidemics (max 2 points): **3***
- *Other countries (max 1 point):**1***

- *This indicator is/will be part of a global system of periodic review (max 1 point): **1***

Maximum 7 points

Summary Results
Overall score: 57/58 (97%)

Key strengths:
- programmatic relevance: Yes
- high reporting rate: Yes
- existing trend data: Yes
- essential for decision-making: Yes
- quality concerns are low: Yes

Key weaknesses: none

UNGASS-related decisions:
Should the indicator be continued to be used?: Yes
Should the indicator be modified?: Yes
Specify modification: age groups expansion
Should the guidance be modified?: Yes
Specify modification: age groups expansion
Does the modification affect trend analysis?: No

Key comments:

- Based on analyses of recent indicator data for a range of countries, UNGASS indicator 12 continues to be a sensitive measure for identifying disparities between orphans/non-orphans. For example, the 2009 OVC Progress Report indicates that compared with non-OVC who live with at least one of their parents, double orphans are less likely to attend school in 45 out of 49 countries reporting this indicator. In 27 out of 31 sub-Saharan countries reporting at two or more points in time, school attendance among double orphans has increased**.** Hence, the orphan/non orphan disparities are worth capturing; in the case of nutrition, sexual debut, the disparities are much less clear. This is also a Millennium Development Goals (MDG) indicator. Hence, continued measurement of this indicator –without modification, is worthwhile, feasible (i.e., using existing data collection tools) and allows for much needed trend data linked to both UNGASS and MDG commitments.

- This indicator is frequently collected as it is based on orphan status rather than the less frequently collected OVC status. However, trends need to be interpreted with caution for time points between data drawn from different surveys: although DHS and MICS have similar standards for implementation, differences do exist.

- The proposed investigation for indicator improvement needs to address the following issues: (a) the current measurement of 'school attendance' is a poor proxy for what can be considered 'adequate' attendance. However, a 'minimum required attendance' would need to be agreed (often this is considered to be not less than 80% of class time) and the feasibility of such a measure as a 'standardized global indicator' for which it is feasible to collect good quality data needs to be carefully considered; (b) the current age range cannot be correlated to primary school age or to lower secondary school age which makes it difficult to work with in educational settings. In addition, attendance rates often show a sharp decline from primary to secondary school (especially when primary school education is compulsory); hence, the children currently included in the numerator and denominator are subject to different attendance prevalence.

- The investigation of the feasibility and programmatic significance of the proposed changes are considered to be of utmost importance. However, a multi-stakeholder, standards-based, consensus process for identifying an existing indicator with proven track record or for developing and pilot-testing a new indicator cannot be completed within the time line of the current UNGASS indicator review. The modified or new indicator also needs to be in line with the new MDG which are currently under review.

2.3.3 Modified UNGASS indicator 2. National Composite Policy Index (sub-set of relevant questions)

RECOMMENDATION: This UNGASS indicator should be continued to be measured with minor modifications. The modifications in track changes and the Standards-based assessment are provided in Annex 4.

The following recommendations for modifications were submitted to the Enabling Environment Group for which **follow-up issues should be noted**:

The below recommendations relate to questions in Part A and Part B of the NCPI:

Recommendation 1: Add the following question:

Does the country have guidelines on care and support? Yes / No
If yes, are the following included [check all that apply]:

- Psychosocial care
- Clinical care
- Social and economic support
- Human rights and legal support
- The care and support needs of carers

Follow-up issue: *The Enabling Environment Group rejected the above recommendation but a similar question was added (see track changes below) elsewhere in the NCPI, namely:*

2. Has the country identified the essential elements of a comprehensive package of HIV treatment, care and support services?

Yes *No*

If yes, briefly identify the elements and what has been prioritized: [write in]

No standards-based rationale was provided for this decision.
In response, it should be noted that (a) while the NCPI is the indicator with highest response rate among the UNGASS indicators, the response rate for open text boxes within the NCPI is low; (b) responses in open text boxes serve as individual country examples only as the information is non-standardized across countries and thus, cannot be aggregated. As the purpose of the NCPI as a global indicator is to aggregate data across countries, the rejection of the recommended additional question is counter-productive to the intent for including the question.

Recommendation 2: Add the following question:

Does government provide any social transfers or support? [check all that apply]

- Pensions
- Availability of free primary health care and ART for the poor
- Free and/or subsidized educational support for poor primary and secondary school children
- Disability grants
- Child grants
- Micro-finance/credit
- Start-up kits for income generation
- Food and nutrition assistance
- Agricultural inputs

Follow-up issue: *The Enabling Environment Group modified this recommendation to:*

> *'Does the government have a policy or strategy in place to provide social and economic support to people infected/affected by HIV? Yes/No. Please clarify which social and economic support is provided: [write in]. A footnote includes some examples.*

The decision for this modifications was stated as 'for the reason that a lot of 'checklists' are already included in the NCPI'. No standards-based rationale was provided for why this particular checklist was not included and perhaps (an)other checklist may be deleted instead.

In response, it should be noted that (a) while the NCPI is the indicator with highest response rate among the UNGASS indicators, the response rate for open text boxes within the NCPI is low; (b) responses in open text boxes serve as individual country examples only as the information is non-standardized across countries and thus, cannot be aggregated. As the purpose of the NCPI as a global indicator is to aggregate data across countries, the rejection of a standardized response list is counter-productive to the intent for including the question; (c) the footnote as specified by the Enabling Environment Group is incorrect.

Recommendation 3: Add the following care and support service items to the existing question and list service items under 2 headings: (a) treatment; (b) care and support. This will highlight clearer that the care and support services listed should not be restricted to those provided in clinical settings only, but also those provided in non-clinical (i.e., community) settings.

2.1 To what extent have the following HIV and AIDS treatment, care and support services been implemented?

HIV and AIDS treatment, care and support service [NOTE: the following list of services is to be ordered under the headings (a) Treatment (then list all *items) and (b) Care and Support (then list all **items)]	The majority of people in need have access		
a. Antiretroviral therapy*	*Agree*	*Don't Agree*	*N/A*
b. Nutritional care*	*Agree*	*Don't Agree*	*N/A*
c. Paediatric AIDS treatment*	*Agree*	*Don't Agree*	*N/A*
d. Sexually transmitted infection management*	*Agree*	*Don't Agree*	*N/A*
e. Psychosocial support for people living with HIV and their families**	*Agree*	*Don't Agree*	*N/A*
f. Home-based and community-based care**	*Agree*	*Don't Agree*	*N/A*
g. Palliative care**	*Agree*	*Don't Agree*	*N/A*
h. ~~and~~ Ttreatment of common HIV-related infections*			
h. HIV testing and counselling for TB patients*	*Agree*	*Don't Agree*	*N/A*
i. TB screening for HIV-infected people*	*Agree*	*Don't Agree*	*N/A*
j. TB preventive therapy for HIV-infected people*	*Agree*	*Don't Agree*	*N/A*
k. TB infection control in HIV treatment and care facilities*	*Agree*	*Don't Agree*	*N/A*
l. Cotrimoxazole prophylaxis in HIV-infected people*	*Agree*	*Don't Agree*	*N/A*
m. Post-exposure prophylaxis (e.g., occupational exposures to HIV, rape)*	*Agree*	*Don't Agree*	*N/A*
n. HIV treatment services in the workplace or treatment referral systems through the workplace*	*Agree*	*Don't Agree*	*N/A*
o. HIV care and support in the workplace (including alternative working arrangements)**	*Agree*	*Don't Agree*	*N/A*

Additions:

- early infant diagnosis*
- PMTCT, including responding to new WHO guidelines on ARV

provision to pregnant women, continuing post-delivery and for infants*
- Pre-ART package for PLHIV who are not yet eligible for ART*
- ART referral and follow-up*
- Socioeconomic support**

p. Other services (write in)

Follow-up issue: *The Enabling Environment Group did not accept all of the additional service elements. No standards-based rationale was provided for why some services were included and not others. The Group also did not include the requested listing under the two headings for the stated reason that they were not adequately expert in this field to judge which services should be listed under which heading.*
In response, there should be a clear rationale for excluding certain recommended service items from the list; the issue about listing services under each of the two headings can easily be resolved by obtaining input from the treatment experts on the proposed division by the Care and Support Group (see items and items**).*

In conclusion, all recommendations from the Care and Support Consultation Group (as per included in this document) should be included in the final version of the NCPI as they are supported by a favorable standard-based assessment and compliment the limited number of quantitative UNGASS indicators (i.e., 3) proposed for care and support in non-clinical settings.

2.3.4 New UNGASS indicator. Percentage of women and men (aged 15-64) expressing accepting attitudes towards people living with HIV

RECOMMENDATION: This existing indicator with a proven track record should be included in the UNGASS indicator set.

Stigma and discrimination are widely recognized as barriers to accessing HIV prevention, treatment, care and support services. However, the negative effects of stigma and discrimination are particularly pertinent within the context of care and support programs for those infected and affected by HIV and AIDS in *non-clinical settings* (i.e., community settings). Hence, the Care and Support Consultation Group strongly endorsed the inclusion of an existing indicator with proven track record in the UNGASS indicator set. The proposed indicator is a recommended core indicator for national AIDS programs (see indicator #14 in *Guidance and Specifications for Additional Recommended Indicators. Core Indicators for National AIDS Programmes. Geneva: UNAIDS, 2008*). These indicators -including the stigma indicator, are recommended for inclusion in national indicator sets in addition to the UNGASS indicators. They were selected and endorsed by a multi-stakeholder, consensus process and endorsed by the MERG. Their selection pre-dates the development and agreement on the MERG Indicator Standards. However, as provided in this document, the assessment of the stigma indicator according to the MERG Indicator Standards shows that this is a feasible and worthwhile indicator to collect and for which data is already available for a range of countries.

A. REQUESTED INDICATOR INFORMATION for the new *UNGASS indicator: Percentage of women and men aged 15-64 expressing accepting attitudes towards people living with HIV*.

Note: The following full indicator description is provided according to the format currently used in the Additional Recommended Indicators manual.
Source: *Guidance and Specifications for Additional Recommended Indicators. Geneva: UNAIDS, 2008. [Addendum to UNGASS. Monitoring the Declaration of Commitment on HIV/AIDS. Guidelines on Construction of core indicators. 2008 Reporting. Geneva: UNAIDS April 2007.*]
(http://data.unaids.org/pub/BaseDocument/2009/20090305_additionalrecommendedindicators_finalprintversio_en.pdf) [Additional Recommended Indicator #14, p.38-39]

TITLE: Accepting attitudes towards PLHIV

PURPOSE:
This indicator measures accepting attitudes toward people living with HIV among women and men aged 15-64 [Note: age groups expansion].
HIV-related stigma refers to unfavourable attitudes, beliefs, and policies directed toward people living with HIV and their family members, close associates and communities. HIV-related stigma can reduce the effectiveness of programmes and services designed for those living with HIV and those who are affected by the disease. For example, studies have shown that some families with orphans have chosen not to receive relief services in order to avoid the stigma attached to these benefits. Other studies found that some families cut themselves off from social support networks long before an AIDS death occurs in the family in order to avoid HIV-related stigma.
HIV awareness programmes are designed to increase accepting attitudes toward people living with HIV or those perceived to be living with HIV. This indicator provides a measure of the effectiveness of HIV awareness programmes and can highlight whether more needs to be done to counter HIV-related stigma.

APPLICABILITY: All countries.

DATA COLLECTION FREQUENCY:
Preferred: every 2 years; Minimum: Every 4-5 years.

MEASUREMENT METHODOLOGY:
Population-based survey.

MEASUREMENT TOOLS:
Population-based survey tools, such as the AIDS Indicator Survey (AIS) or Demographic and Health Survey (DHS) can be used.

METHOD OF MEASUREMENT:
Definition: Percentage of women and men aged 15-64 expressing accepting attitudes towards people living with HIV, disaggregated by sex (female, male), age (15-19, 20-24, 25-49, 50-54, 55-59, 60-64), and education level (none, primary, secondary or higher). [Note: age groups expansion]

Numerator: Number of women and men aged 15-64 who report accepting attitudes towards people living with HIV. [Note: age groups expansion]

Denominator: All respondents aged 15-49 who have heard of HIV.

Calculation:

$$\frac{\textit{Number of women and men aged 15-49 who report accepting attitudes towards PLHIV}}{\textit{All respondents aged 15-64 who have heard of HIV [Note: age groups expansion]}} \times 100$$

HOW TO MEASURE IT:
The **numerator** is calculated by first asking survey respondents if they have ever heard of HIV. If they answer yes, then they are asked a series of questions about people with HIV, including:

1. If a member of your family became sick with the HIV virus, would you be willing to care for him or her in your household?;
2. If you knew that a shopkeeper or food seller had the HIV virus, would you buy fresh vegetables from him/her?;
3. If a female teacher has the HIV virus but is not sick, should she be allowed to continue teaching in school?; and
4. If a member of your family became infected with the HIV virus, would you want it to remain a secret?

Only respondents who report an accepting or supportive attitude on all four of these questions is counted in the numerator. An accepting attitude for the respective questions is considered to be (1) yes; (2) yes; (3) yes; and (4) no.

The **denominator** consists of all respondents in the survey who have heard of HIV.

Disaggregation: **Age group:** 15-19 years; 20-24 years; 25-49 years, 50-54 years, 55-59 years, 60-64 years [Note: age groups expansion]
Education: none, primary, secondary or higher.
Sex: female, male.

INTERPRETATION:
This indicator measures the percentage of the population with accepting attitudes toward people living with HIV, and it provides a measure of HIV-related stigma. It is not, however, a perfect measure of HIV-related stigma. While a low value for the indicator suggests high levels of HIV-related stigma, a high value for the indicator could be interpreted in several ways: that there are low levels of HIV-related stigma, or that people know they should not discriminate and therefore report accepting attitudes. High scores may also reflect the respondent's limited personal experience with HIV.
Another limitation of this indicator is that there is frequently not a direct relationship between attitudes and behaviour. What people actually do in the face of HIV may well differ from what they say they would do. Some studies have found, for example, that people expressing very negative attitudes toward those living with HIV actually provide supportive care for an HIV-infected relative in their own home. On the other hand, some people who deny having negative attitudes towards people with HIV may actively discriminate against them in specific settings, such as in the provision of health care.

B. MERG INDICATOR STANDARDS ASSESSMENT

1. Is the indicator fully described?

MERG Indicator Standards [MERG Indicator Standard 3] **Assessment Result: 13/14**

- *Title and definition (max 2 points):* ***2***
- *Purpose and rationale (max 2 points):* ***2***
- *Method of measurement (max 4 points):* ***4***
- *Collection method (max 1 point):* ***1***
- *Measurement frequency (max 1 point):* ***1***
- *Details of any disaggregation (max 1 point):* ***1***
- *Guidelines on how to interpret changes in the indicator (max 1 point):* ***1***
- *Strengths and weaknesses of the indicator (max 1 point):* ***1***
- *Additional sources of information (max 1 point):* ***0***

Maximum 14 points

Conclusion: The indicator has a high score for this Standard. It should, therefore, allow for *continued* standardized data collection and directly comparable data across countries and over time.

2. How will the data from this indicator be used?

MERG Indicator Standards [MERG Indicator Standard 1] **Assessment Result: 10/11**

- *This indicator measures performance against a key international commitment, for example, MDGs, UNGASS (max 1 point):* ***0*** *[not currently, but stigma reduction is a key area for focus for AIDS programs*
- *This indicator is relevant to some/all country contexts (max 1 point):* ***1***
- *This indicator produces information which is needed by and useful to in-country stakeholders (max 1 point):* ***1***
- *Information from this indicator would be helpful/essential at global/international level to distinguish performance of different countries in responding to HIV and AIDS (max 2 points):* ***2***
- *Information from this indicator would be helpful/essential for those managing national responses to HIV and AIDS (max 2 points):* ***2***
- *Information from this indicator is helpful/essential at global/international level to allow decisions to be made in terms of programme development and resource allocation (max 2 points):* ***2***
- *Information from this indicator is helpful/essential at national level to allow decisions to be made in terms of programme development and resource allocation (max 2 points):* ***2***

Maximum 11 points

Conclusion: The indicator has a high score for this Standard. It should, therefore, allow for *continued* standardized data collection and directly comparable data across countries and over time.

3. What steps have been taken to ensure the indicator is harmonised with other indicators?

MERG Indicator Standards [MERG Indicator Standard 1] **Assessment Result: 4/5**

- *This indicator is accepted and used by all major international partners working in this technical area (max 1 point):* ***extent not known***
- *This information is not available from other indicators (max 1 point):* ***1***
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding detailed description (max 1 point):* ***1***
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding systems for data collection (max 1 point):* ***1***
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding time frames for data collection (max 1 point):* ***1***

Maximum 5 points

Conclusion: The indicator has a high score for this Standard. It, therefore, does not present major challenges in terms of indicator harmonization.

4. What process has been followed to ensure the technical value of this indicator?

MERG Indicator Standards [MERG Indicator Standard 2] **Assessment Result: 9/9**

- *The indicator is significant and important within a particular technical field (max 1 point):* ***1***
- *The indicator provides a clear and focused measure of progress in a particular technical area (max 1 point):* ***1***
- *There is a clear understanding of what changes in the value of the indicator mean, how they should be interpreted and what kind of action to take as a result (max 1 point):* ***1***
- *The indicator is sensitive to pick up small changes in performance (max 1 point):* ***1***
- *The indicator is reliable and sensitive (max 1 point):* ***1***
- *The indicator is valid and specific (max 1 point):* ***1***
- *The indicator has previously been reviewed by people with expertise in the relevant technical area (max 1 point):* ***1***
- *The indicator has previously been reviewed by people with monitoring and evaluation expertise, including particularly indicator design (max 1 point):* ***1***
- *The indicator has previously been reviewed by people with experience in a wide range of countries with different types of HIV epidemics (max 1 point):* ***1***

Maximum 9 points

Conclusion: The indicator has a high score for this Standard. Hence, it will continue to provide good quality data from DHS, AIS and MICS.

5. What evidence is there that it will be feasible to track this indicator?

MERG Indicator Standards [MERG Indicator Standard 4] **Assessment Result: 12/12**

- *The number of countries in which systems and mechanisms needed to collect data for this indicator are functioning (max 3 points):* ***3***
- *The number of countries in which systems and mechanisms needed to interpret and use data for this indicator are functioning (max 3 points):****3***
- *The number of countries in which this indicator is already included in national AIDS M&E systems (max 3 points):* ***3***
- *Evidence is presented that financial and human resources are available to measure this indicator (max 2 points):* ***3***
- *Evidence is presented that measuring this indicator is worth the cost (max 1 point):* ***1***

Maximum 12 points

Conclusion: The indicator has a high score for this Standard.
Estimates of the systems required: no additional requirements as the indicator is already incorporated in standard survey instruments used for collecting other relevant UNGASS and national indicator data.
Estimates of the resources required: no additional requirements.

6. Where is the indicator currently being used? Where has it been field-tested?

Data availability: Source: *Progress report for children affected by HIV/AIDS, UNICEF, December 2009*:
countries reporting: 39 countries for data on men (representing 33% of global male population); 70 countries for data on women (representing 40% of global female population). Note: This indicator is more frequently collected for women because, with a few exceptions, the MICS does not implement a questionnaire for adult men.
Time period: AIS, DHS, MICS or other survey conducted in 2003 or later
countries with two or more measurements: 3 (among women); 3 (among men)

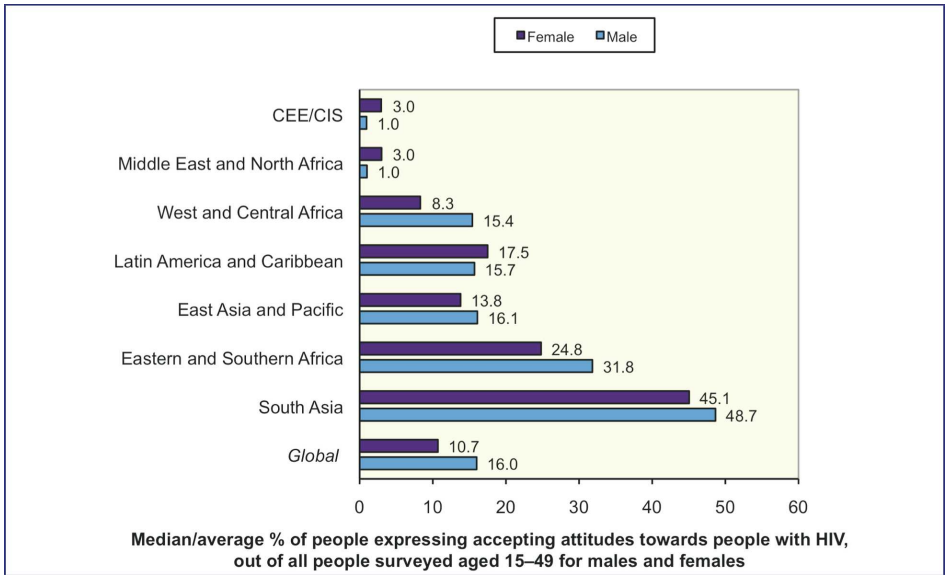
The specific break-down by region of countries with data available is as follows:

CEE/CIS: 4 (male); 14 (female)
Middle East and North Africa: 1 (male); 5 (female)
West and Central Africa: 14 (male); 19 (female)
Latin America and Caribbean: 3 (male); 9 (female)
Eastern and Southern Africa: 12 (male); 15 (female)
East Asia and Pacific: 3 (male); 6 (female)
South Asia: 2 (male); 2 (female)

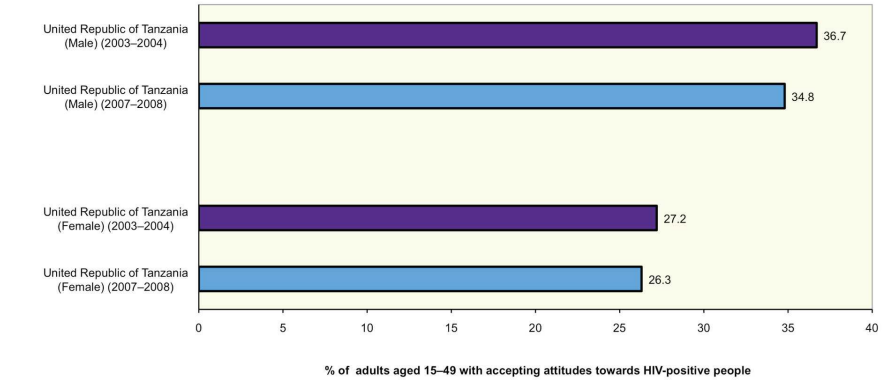
Global: 39 (male); 70 (female)

Although there is regional variation in data availability, data have been collected in *all* regions. This is clearly indicating that it is possible to collect these data everywhere. As already indicated above, there are no additional requirements in terms of systems or resources as the indicator is already incorporated in standard survey instruments used for collecting other relevant UNGASS and national indicator data.

Page 53, Figure 23: Percentage of people expressing accepting attitudes towards people living with HIV, out of all people surveyed aged 15–49 for males and females, 2003-2008 (regional medians/averages, in ascending order by female per cent). **[Source:** AIS, DHS, MICS, and other nationally representative surveys, 2003–2008].



Page 53, Figure 24: United Republic of Tanzania: Time trend in percentage of people expressing accepting attitudes towards people with HIV out of all people surveyed aged 15–49 for males and females, 2003-2008* **[Source:** United Republic of Tanzania AIS, 2003–2004, and HMIS, 2007–2008].



MERG Indicator Standards [MERG Indicator Standard 5] **Assessment Result: 7/7**

- *The number of countries in which the indicator has been field-tested or used operationally*
  - *Country's national program (max 3 points): **3***
  - *Countries with similar epidemics (max 2 points): **3***
  - *Other countries (max 1 point): **1***
- *This indicator is/will be part of a global system of periodic review (max 1 point):*

Maximum 7 points

Conclusion: The indicator has a high score for this Standard. It will continued to be collected through DHS, AIS and MICS.

Key Results

Overall score: 55/58 (95%)

Key strengths:
There is evidence for:
- programmatic relevance: Yes
- high reporting rate: Yes (based on representing minimum 30% of global population)
- essential for decision-making: Yes
- quality concerns are low: Yes

Key weaknesses:
- existing trend data: No

UNGASS-related decisions:

Should the indicator be added to the UNGASS indicator set? Yes
Should the indicator be modified?: Yes
Specify modification: age groups expansion
Should the guidance be modified?: Yes
Specify modification: age groups expansion
Does the modification affect trend analysis?: No

Key comments:

- The *2009 Progress Report* indicates that CEE/CIS and MENA have the lowest level of accepting attitudes, while SA has the highest levels. In all regions except CEE/CIS, LAC and MENA, men are more likely to have accepting attitudes than women. The results show the level of discriminatory attitudes expressed by adults towards HIV-positive adults; the extent to which children infected and affected by HIV/AIDS are stigmatized by adults or by other children can only be inferred.

- The recommendations on the stigma indicator (i.e., the proposed new UNGASS indicator) were submitted for feed-back to the Enabling Environment Group. Feedback received on the stigma indicator (verbatim quote): "*As we understand stigma to be part of what is meant by 'enabling environment', one of our Expert groups looked carefully at the possible inclusion of a stigma indicator in the core set of quantitative UNGASS indicators. Their work leveraged a much larger process – jointly led by the Global Network of People Living with HIV (GNP+), International Center for Research on Women (ICRW), International Planned Parenthood Federation (IPPF) and UNAIDS – that has been exploring this issue for some time.*
Based on this and other work, we very much agree with your team that addressing stigma is a critically important part of a country's AIDS response and, if an appropriate indicator can be developed, included as part of UNGASS monitoring. At this time, however, we concluded that neither an existing nor newly proposed stigma indicator was ready for inclusion in the UNGASS indicator set. There was consensus that existing indicators did not capture and measure stigma sufficiently well and that newer, and potentially promising indicators, have not necessarily received the full validation and field-testing required to be acceptable by the MERG. Among the indicators considered by our Expert group was 'Accepting Attitudes Toward People Living with HIV.' It was noted that field-testing of this indicator yielded some weaknesses in its validity and that DHS may replace this indicator once the MERG accepts a new one.
Consequently, the Enabling Environment consultation group's perspective is that while stigma should be tracked in the UNGASS set, we recommend waiting for the next round of revisions to the UNGASS indicators to ensure that the most appropriate and rigorously field-tested stigma indicator is selected."
It should be noted that, although agreed at the UNGASS meeting (5-6 Oct 2010) with all Consultation Groups, no further information was provided in writing to the Care and Support Core Team before this document was re-submitted on 11 October 2010.

  While the Care and Support Consultation Group agrees with the need for a stronger stigma measure, yet to be developed and pilot-tested according to MERG Standards, the Group recommends the existing stigma indicator as its standards-based assessment has an overall high score, a standardized data collection tool is in place and will continue to be used to collect this indicator, and data is already available from a range of countries as a basis of much needed trend analysis. As indicated above, this indicator was also approved through a multi-agency process and through the MERG in 2008 as part of the 'Additional Recommended Indicators'.

- The following existing indicators with full indicator specifications were considered for potential inclusion in the UNGASS indicator set:
  1. Ratio of OVC versus non-OVC aged 12-17 with an adequate score for psychological health [source: OVC indicator manual]
  2. Ratio of food insecure households with OVC compared to households without OVC [source: OVC indicator manual]
  3. Number of eligible clients who received food and/or nutrition services [source: PEPFAR]

  Based on the standards-based assessment of each of these indicators, they were considered NOT to be viable additions/alternatives for inclusion in the UNGASS indicator set.

3. OTHER RECOMMENDATIONS

3.1 Recommendation for the expansion of the age range for UNGASS indicators collected through population-based surveys

RECOMMENDATION: The age range in population-based surveys should be expanded to include older people up to 64 years old.

Evidence-based rationale for the inclusion of older people in UNGASS indicators:

Epidemic monitoring and progress reporting

Older people (aged 50 and over) are widely excluded from systems used to track the HIV epidemic and progress in responding to it. Data on the epidemic was initially collected for people aged between 15 and 49, the widely used reproductive age range. Yet, the HIV epidemic does not only affect those having children. In 2006, UNAIDS recognized that 'the burden of disease extends beyond the age of 49' and stated that a 'substantial proportion of people living with HIV and AIDS were aged 50 years and older'.[10] As a result, UNAIDS and WHO estimates for number of people living with HIV, new infections and AIDS-related deaths were expanded beyond the 15-49 year age bracket to include all adults aged 15 and over. HIV prevalence data remained restricted to the younger age group.

The impact of HIV on older people

Older people are affected by HIV in two ways: (1) as people living with HIV; and, (2) as carers for others living with the virus and children orphaned or made vulnerable by AIDS. Because of the way the epidemic is monitored, limited data exists to demonstrate the nature and scale of the epidemic among older people. However, available data clearly demonstrates the need to include older people in the HIV response. Where prevalence data exists for older people, the general trend shows that prevalence for those aged 50-54 is equal to the national prevalence and often significantly higher for men. Prevalence decreases but remains significant for people aged 55-59 and over [Table 1].

[10] UNAIDS 2006 Report on the global AIDS epidemic

Table 1. HIV prevalence among older people

Country/Age Group	Kenya[11]		South Africa[12]		Mozambique[13]		Botswana[14]		Swaziland[15]	
	F	M	F	M	F	M	F	M	F	M
50-54	7.5	8.3	10.2	10.4	12.7	10.6	22.2	28.8	24.3	28.3
55-59	4.7	2.3	7.7	6.2	8.8	7.2	25.1	19.5	9.6	17.4
60-64*	1.7	3.4	1.8	3.5	3.2	5.1	14.4	16.7	7	13.3
National Prevalence[#]	8.8	5.5	13.6	7.9	13.1	9.2	28.2	20	31.1	19.7

*60+ in Swaziland and South Africa
[#]15-49 in Kenya, Mozambique and Swaziland, 15-64 in Botswana, total population of all ages South Africa

Data presented by UNICEF in 2007, showed that between 40 and 60 percent of orphaned and vulnerable children in East and Southern Africa were being cared for by grandparents.[16] A report published by the World Bank suggested similar findings with high proportions of orphans living with their grandparents. Figures were particularly high for double orphans, with 63.1% in Kenya, 64.2% in Namibia and 81% in Zimbabwe living with their grandparents.[17] Older people also play a crucial role in caring for adults living with HIV. In Cambodia, research showed that an older parent was the main personal carer in 80% of cases where an adult child had died as a result of AIDS.[18] These statistics demonstrate the huge contribution being made by older carers in the response to the epidemic and the need to ensure they are reached with appropriate information and support services.

The use of DHS data for UNGASS reporting

Seven of the current 25 core UNGASS indicators are monitored using data from population-based surveys, usually demographic and health surveys (DHS). Of these, 3 indicators focus on adults' access to testing, multiple sexual partnerships and condom use and are currently restricted to the 15-49 year age group, neglecting people below the age of 15 and over the age of 49. The same is true for some of the additional recommended indicators (i.e., indicators recommended for national AIDS programs in addition to the UNGASS indicators), including on accepting attitudes towards people living with HIV. This is due to the age bracket commonly applied to DHS, usually 15-49, with some surveys including men up to 59 years. These age brackets were originally recommended for DHS because the majority of

[11] Government of Kenya 2009 Kenya AIDS indicator survey 2007 Final Report http://www.aidskenya.org/public_site/webroot/cache/article/file/Official_KAIS_Report_20091.pdf
[12] HSRC 2009 South Africa National HIV prevalence, incidence, behaviour and communication survey 2008 http://www.mrc.ac.za/pressreleases/2009/sanat.pdf
[13] Government of Mozambique 2010 Insida 2009
[14] Government of Botswana 2009 AIDS Indicator Survey III
[15] Government of Swaziland 2008 Swaziland demographic and health survey 2006-07 http://www.measuredhs.com/pubs/pdf/FR202/FR202.pdf
[16] UNICEF 2007 The state of the World's Children: Women and children, the double dividend of gender equality
[17] Beegle K et al 2008Orphanhood and the living arrangements of children in sub-Saharan Africa, World Bank
[18] Knodel J et al 2007 The effects of elderly parents in Cambodia of losing an adult child to AIDS, Population and development review 33(3):479-500

the survey was focused on issues of reproductive health and family planning. The DHS now includes topics of relevance to other age groups, including HIV and AIDS, female genital cutting, gender/domestic violence and women's empowerment, making the limited focus on those between the ages of 15 and 49 problematic.

DHS have included questions on people's knowledge, attitudes and behaviors in relation to HIV since 1988, but people aged 50 and over have been excluded in over 20 years worth of data. The reliance of UNGASS reporting on data from the DHS has led to a lack of understanding of the impact of HIV and AIDS on older people at both national and international levels, and a subsequent lack of attention to this group in the response. The neglect of older people in indicators on sexual behavior has perpetuated the assumption that older people are not sexually active and not at risk of being infected. In recent years, some DHS and other national population-based surveys have included people over the age of 49 and have provided useful data to demonstrate the impact of HIV and AIDS on older people and their neglect from, and need for access to services.

The following sections will address the specific need to collect data for people aged 50 and over in relation to the issues addressed by UNGASS indicators: accepting attitudes; multiple sexual partnerships; condom use; and access to testing. Removing the 15-49 year age bracket for these indicators would not disrupt trend data if data were disaggregated by age maintaining a 15-49 set for comparison with previous years. In order to gain a comprehensive understanding of the needs of older people in relation to HIV and AIDS (and other key issues addressed by DHS and mentioned above), a broader review of the population included in these surveys is needed. We recommend including 50-54, 55-59, and 60-64 year olds.

Percentage of women and men (aged 15-49) expressing accepting attitudes towards people living with HIV

Stigma and discrimination does not only occur within certain age groups. All people, including older people, can both discriminate and be discriminated against. As demonstrated by the statistics above, older people are primary carers for people living with HIV and children orphaned or made vulnerable by AIDS. It is important to ensure that these older carers are looking after their family and community members in an appropriate way and are not discriminating against them. Older people living with and affected by HIV often face stigma and discrimination themselves, often on multiple grounds, as a result of their HIV status, age and sex. Accepting attitudes towards older people affected by HIV must also be ensured.

Some countries that have included people beyond the age of 49 in the DHS, present data on accepting attitudes among the older age group which can be compared with the younger population currently captured by the UNGASS indicator [Figure 1, Table 2]. Data from Swaziland[19] and Botswana[20] shows that, in general, older people are less likely to demonstrate accepting attitudes towards people living with HIV than younger people. The different attitudes between the two age groups differ depending on the indicator being addressed. The general lower level of acceptance among older people in Swaziland and Botswana points to the need to collect data for those aged 50 and over to gain a comprehensive understanding of the situation in other countries to assess whether this trend is seen elsewhere, and to ensure older people are included in efforts to reduce stigma and discrimination.

[19] Government of Swaziland 2008 Swaziland demographic and health survey 2006-07 http://www.measuredhs.com/pubs/pdf/FR202/FR202.pdf
[20] Government of Botswana 2009 AIDS Indicator Survey III

Figure 1. Older people's attitudes towards people living with HIV

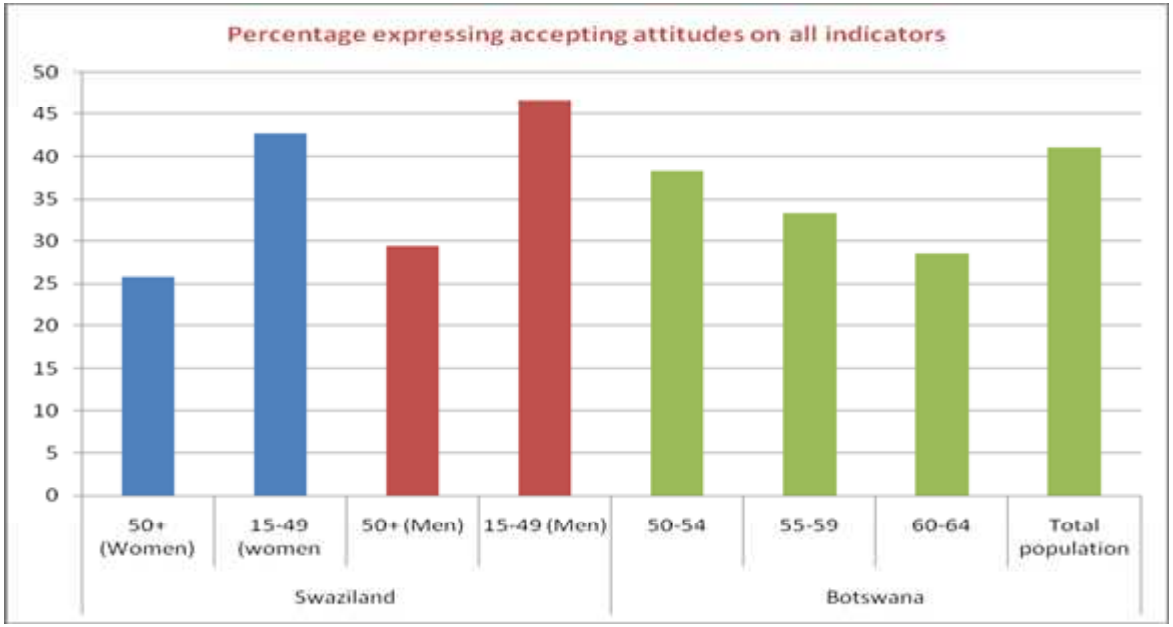


Table 2. Older people's attitudes towards people living with HIV

	Swaziland				Botswana			
	50+ (F)	15-49 (F)	50+ (M)	15-49 (M)	50-54	55-59	60-64	Total population
Willing to care for a family member with HIV	90	92	89.7	91.6	97.4	95.9	95.1	94.9
Would buy vegetables from a shopkeeper living with HIV	51.3	74.3	50.4	78	77	68	61.6	76.3
Say that a teacher living with HIV should be allowed to continue teaching	69.6	90.6	70.8	89.3	79.8	74.1	63.3	82.7
Would not want to keep secret that a family member is living with HIV	60.2	61.4	66.9	64.8	55.5	57.2	58.1	60.1
Would share a meal with a person living with HIV					36.3	25.9	25.7	33.2
Percentage expressing accepting attitudes on all indicators	25.8	42.7	29.4	46.6	38.3	33.3	28.5	41.1

A likely explanation for lower levels of acceptance among older people is their neglect in HIV education and awareness raising programs, and a resulting lack of knowledge and awareness. The data below supports this explanation and demonstrate the need to target older people with HIV education and information. This lack of knowledge of HIV and AIDS and lower levels of acceptance among older people is not only significant in highlighting potential stigma and discrimination, but also because of the role older people play in caring for children. It is important that older carers are equipped with the knowledge to be able to educate those in their care and reduce the likelihood of children growing up with negative attitudes.

Table 3. Older people's knowledge of HIV and AIDS

	Swaziland				Botswana			
	50+ (F)	15-49 (F)	50+ (M)	15-49 (M)	50-54	55-59	60-64	Total population
A healthy looking person can have HIV	78.9	96.1	85.8	95.7	87.9	80.4	74.4	84.5
HIV cannot be transmitted through mosquito bites	39.7	65.7	44.4	66.1	33.9	31.0	25.1	59.3
HIV can not be transmitted by witchcraft/ supernatural means	72.8	92.3	75.5	91.7	71.1	70.1	61.2	81.0

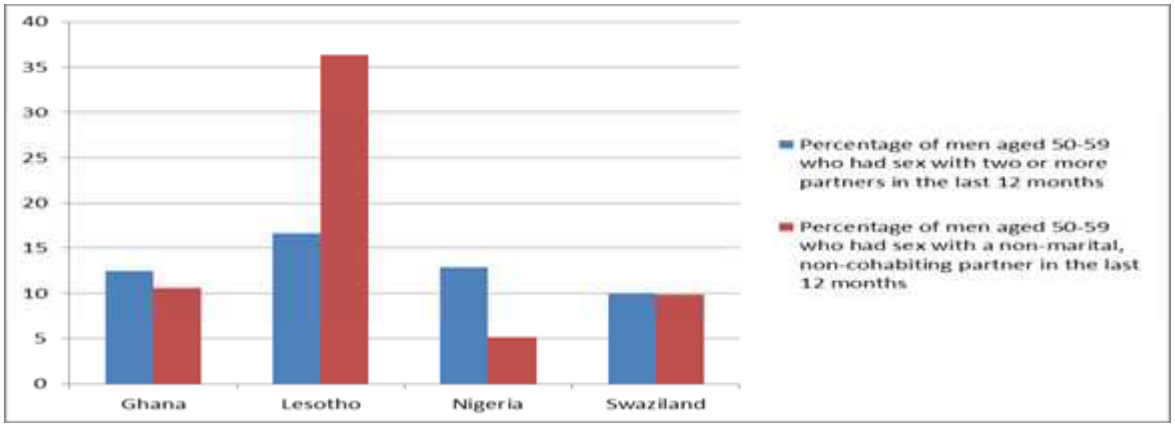
Percentage of women and men (aged 15-49) who have had sexual intercourse with more than one partner in the last 12 months

Prevalence data show that older people are living with HIV. This is probably due to both older people becoming newly infected and because people are living longer as a result of increased access to ART. The impact of ART will likely be less pronounced in the developing world where drugs have only been available for a relatively short time.[21] Data from Brazil has shown that incidence among those aged 50 and over doubled between 1996 and 2006, prompting the Government to launch a new campaign: 'sex has no age, nor has protection'.[22] The campaign recognized that older people were being infected as a result of unsafe sex.

There has been little research into sexual activity of older people in the developing world, but it must be recognized that people remain sexually active into their 50s and beyond. Further information is needed on older people's sexual behavior and risk of HIV infection. Some countries that have included men up to age of 59 in the DHS, provide data on the sexual behavior of this age group, including on multiple sexual partners and higher risk sex [Figure 2].[23] An UNGASS indicator addressing multiple sexual partnerships or concurrent sex must include those over the age of 49 to give a clearer picture of the behavior of older people and their need for education and information to protect themselves. Data is needed for women over 49 alongside that for men. Data from Swaziland for those aged 50 and over indicates a higher rate of higher risk sex among older women than older men (11.8% women, 9.9% men).[24]

[21] Schmid G et al 2009 The unexplored story of HIV and ageing, Bulletin of the WHO 2009:87:162
[22] WHO 2009 Unprotected sex has no age, Bulletin of the WHO 2009:87:165-66
[23] The number of people questioned on this and other issues is sometimes very small and further research would be needed to ensure a more comprehensive overview of the situation
[24] Government of Swaziland 2008 Swaziland demographic and health survey 2006-07 http://www.measuredhs.com/pubs/pdf/FR202/FR202.pdf

Figure 2. Higher risk sex among men aged 50-59



Percentage of women and men (aged 15-49) who had more than one sexual partner in the last 12 months reporting the use of a condom during their last sexual intercourse

Recognizing that older people are sexually active, it is important to ensure they are included in HIV prevention and awareness-raising interventions and that they know how to protect themselves. In 2009, UNAIDS recognized that the largest share of new infections in many African countries occur among older heterosexual couples, yet relatively few prevention programs have focused on older adults.[25] UNAIDS was using 'older' to refer to people aged over 24 years. With few prevention programs targeting people aged 25 or over, it is crucial that interventions reaching all age groups are scaled up. However, there is a specific need to target those aged 50 and above. Many studies have shown that older people are less likely than their younger counterparts to practice safer sex[26], a finding supported by data on condom use amongst men aged 50-59 in comparison with the 15-49 year age group [Figures 3, 4].

[25] UNAIDS 2009 AIDS Epidemic update
[26] Schmid G et al 2009 The unexplored story of HIV and ageing, Bulletin of the WHO 2009:87:162

Figure 3. Condom use among men 50-59 and 15-49 who had two or more partners in the last 12 months

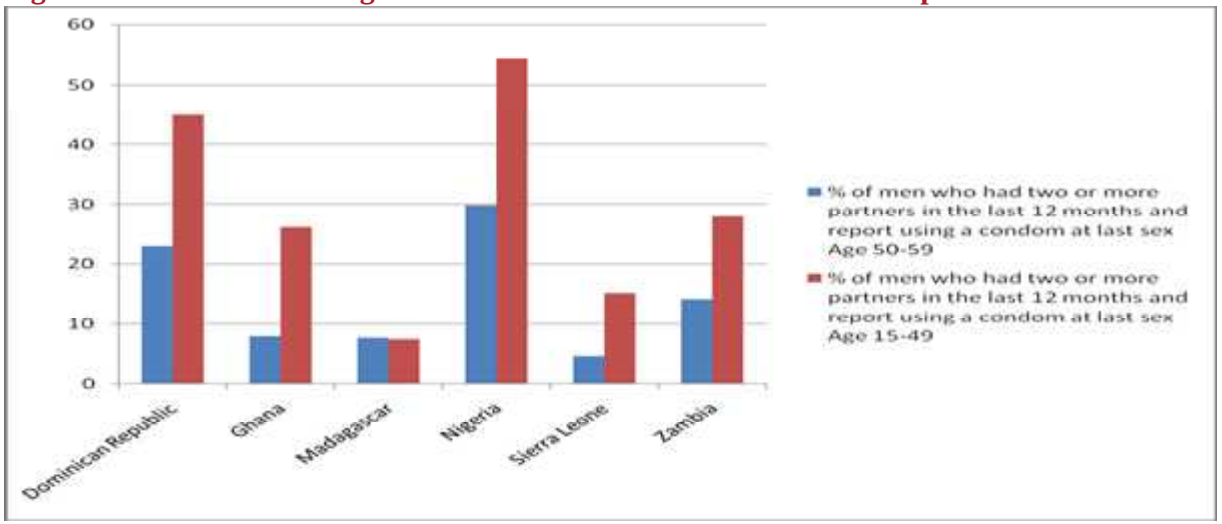
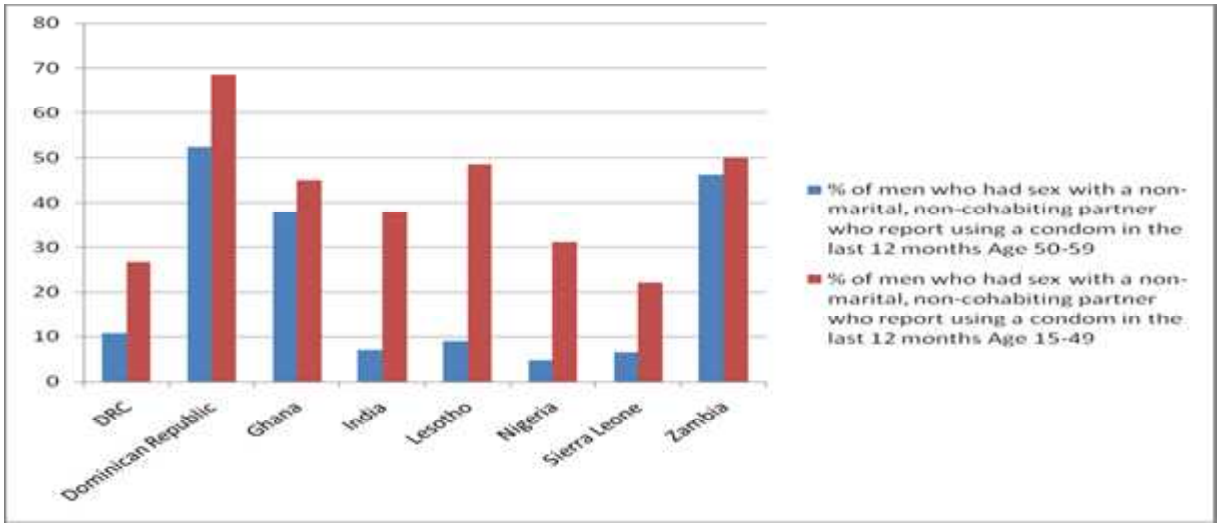


Figure 4. Condom use among men 50-59 and 15-49 who had higher risk sex in the last 12 months



Data also show that older people have less access to HIV and AIDS-related information and less knowledge about how HIV is transmitted and how to protect themselves. Findings from South Africa show that 27.9% of men and 21.2% of women aged 50 and over had correct knowledge of the prevention of sexual transmission of HIV and could reject major misconceptions about transmission. This was the lowest rate of awareness amongst all age groups. Older people were also less likely to have been reached with HIV and AIDS communication messages than other groups with 62.2% of people aged 50 and over having been reached in comparison with 90.2% of 15-24 year olds and 83.6% of those aged 25-49.[27]

Percentage of women and men (aged 15-49) who received an HIV test in the last 12 months and know their results

A major challenge for older people living with HIV is late diagnosis. Research undertaken in France has shown that older people are more likely to have HIV diagnosed late. This is likely due to older people not thinking they are at risk and health professionals being less likely to recommend an HIV test for older people with symptoms suggestive of HIV.[28] Similar findings have been seen in the UK.[29] While studies have found that ART can be as effective in older people as younger people, late diagnosis and initiation of treatment lead to a poorer immunological and virological response.[30]

Data from Swaziland and Botswana demonstrates the need to increase access to testing among older people. Poorer coverage of testing is seen among women aged 50 and over in Swaziland than among women aged 15-49 for all indicators [Table 4]. In Botswana, a similar situation is noted in both men and women.

Table 4. Coverage of testing among women in Swaziland

	% who received results from last HIV test taken in last 12 months	% who know where to get an HIV test	Ever tested and received results	Ever tested	Never tested
Women 50+	10.2	71.1	15.6	18	82
Women 15-49	21.9	91.8	35.8	40.7	59.3

More data is needed about older people's access to testing and, if access is low, the reasons for this. It is important that older people know their HIV status both in order to protect others from infection and so they can access the treatment care and support services they need to live positively.

Although only limited data is available for older people on the issues currently monitored by the UNGASS indicators, the data that does exist demonstrates the importance of including older people in HIV and AIDS monitoring and reporting. Further data is needed to better understand the impact of the epidemic on older people and how best to respond.

[27] HSRC 2009 South Africa National HIV prevalence, incidence, behaviour and communication survey 2008 http://www.mrc.ac.za/pressreleases/2009/sanat.pdf
[28] Cuzin L et al. Immunological and clinical responses to highly active antiretroviral therapy in patients with HIV infection aged > 50 years. Clin Infect Dis, 45: 654 – 657, 2007.
[29] Smith R et al 2010 HIV transmission and high rates of late diagnosis among adults aged 50 and over, AIDS 24 August, volume 24, issue 13.
[30] Cuzin L et al. Immunological and clinical responses to highly active antiretroviral therapy in patients with HIV infection aged > 50 years. Clin Infect Dis, 45: 654 – 657, 2007.

3.2 Recommendation for the development of MERG-endorsed standardized indicators in HIV/AIDS care and support for national AIDS programs

RECOMMENDATION: The Care and Support Consultation Group strongly recommends the development and pilot-testing of a concise set of standardized indicators which address the five essential components of comprehensive HIV/AIDS care and support and which adhere to the MERG Indicator Standards.

The indicator identification, classification and standards-based analysis conducted by Butler and Drew in 2009 (see above), pointed to a large overall number of care and support indicators (220) but a very small number of indicators (7) which are *both* addressing critical components of comprehensive care and support in non-clinical settings *and* are of sufficient quality (as per MERG Indicator Standards) to be considered as viable indicators. In addition, not all of this limited number of indicators are intended for use at the national level (i.e., included in the standardized indicator sets of national AIDS programs for regular data collection and reporting) from which indicators with a good track record can be selected for inclusion in the global UNGASS indicator set. Hence, the Care and Support Consultation Group was severely limited in its choice of appropriate existing indicators as enhanced or alternate indicators for inclusion in the UNGASS set. The general lack of standardized indicators in this area, was also confirmed by the web-based survey on current practices in national monitoring and by the analysis of indicators reported to the Global Fund as part of performance-based disbursement of grants.

These findings point to the urgent need for increased indicator harmonization and standardization in this area. Thus, the stakeholder group strongly recommends the development and pilot-testing of a concise set of indicators to be collected by national AIDS programs, addressing the five critical components of comprehensive HIV/AIDS care and support and adhering to the MERG Indicator Standards.

Based on broad agreement during the care and support consultation process, the following key areas were noted as particularly urgent for the development of standards-based indicators and the desirability of including indicators with a proven track record in the global UNGASS indicator set (i.e., the next UNGASS revision round):

(a) Nutrition as an element of both comprehensive HIV/AIDS care and support and comprehensive HIV treatment. Further inter-agency work (including WFP, PEPFAR, WHO, Fanta, UNICEF and other relevant agencies/organizations) is recommended under the auspices of the MERG Indicator Technical Working Group to develop standards-based indicators as part of care and support indicator sets, treatment indicator sets or both.
(b) Clinical care in non-clinical settings.
(c) Psychosocial support.
(d) Care for caregivers.

In addition, an investigation for indicator improvement of UNGASS indicator 12 needs to be undertaken to address the identified issues explained in detail above. This should also, ideally, be conducted by an inter-agency group under the auspices of the MERG Indicator Technical Working Group.

4. REFLECTIONS ON THE UNGASS CONSULTATION PROCESS

- The consultation process was a time-consuming and labor-intensive process; it also required skills and previous experience in working with evidence-based and standards-based indicator development and selection to guide the process with a group of stakeholders of diverse backgrounds.

- The MERG Indicator Standards were an essential tool to support indicator selection, especially in avoiding dominance of 'external' factors in decision-making.

- There is need for a better mechanism for providing a coordinated and harmonized response to 'external' forces to provide support to each of the individual consultation groups in doing the 'right thing' (i.e., using an evidence-based and standards-based approach to indicator selection).

- All UNGASS consultation groups should use an 'identical' process to ensure adequate consultation, transparency, and collaboration across the different groups.

- Consultation and consolidation across groups requires commitment to transparency in decision-making and additional time to resolve cross-cutting issues between different groups.

- The selection of UNGASS indicators for care and support in non-clinical settings was hampered by a lack of standardized indicators with proven track record of national data collection and reporting. There is need for a better mechanism for regular assessment of standardized national level indicators and timely support, where needed, in terms of revision and/or further development of such indicators.

The Care and Support Core Team is available to provide further details regarding the above reflections, as needed.

ANNEX 1. Results from web-based survey on current monitoring practices and data use in HIV/AIDS care and support at national level

Purpose of the survey

The purpose of the web-based survey was to obtain information from a broad group of stakeholders about the **current monitoring practices at the national level in the area of HIV/AIDS care and support**. The information from this consultation was fed into the stakeholder workshop which aims to recommend appropriate UNGASS indicators for global monitoring of progress towards achieving the *Declaration of Commitment on HIV/AIDS* adopted by all 189 UN Member States in 2001 and the Millennium Development Goal of halting and beginning to reverse the HIV epidemic by 2015.

Important information for completion of the survey

- The process for selecting appropriate UNGASS indicators needs to be **transparant and standard-based**. For this reason, you are asked to provide specific and well-documented responses to the survey questions.
- Only indicators for which there is evidence of their **utility to the care and support program and feasibility of data collection** will be considered. For this reason, you are asked to provide your experience with collecting and using **existing indicators**, **not propose new indicators**.
- This survey is about **national indicators only**: indicators that are useful at the **national level** and can be **collected and reported regularly**. It should be noted that national indicators are only intended to provide a small part of the information needed about the national HIV epidemic and response. For effective program management, additional sources of information should be obtained through a variety of methods, but these are **not** the subject of this survey.
- This survey is about **indicators for the below specified aspects of HIV/AIDS care and support**. This does not imply that the other aspects of care and support as included in the above comprehensive definition, are not important. The remaining aspects of care and support are covered by other consultation groups in the UNGASS indicator review process (i.e., clinical aspects) or by the National Composite Policy Index (i.e., human rights and legal aspects).

Survey questions

CONSULTATION ON HIV/AIDS CARE AND SUPPORT INDICATORS AND DATA USE AT NATIONAL LEVEL

Thank you in advance for providing the following information. This will be used to understand who contributed to this consultation and to contact you directly in case we need further clarification or additional follow-up.

- Name:
- Organization:
- Country:
- e-mail:

Instructions:

It is essential that you provide specific information. Responses only indicating yes/no without *any* additional information can not be considered for the reasons indicated under 'IMPORTANT INFORMATION' above. We do acknowledge that *not all* requested additional information may be available to you, but ask that you provide *as much detail as possible.*

1. Psychosocial aspects:
including counselling services, emotional and spiritual support (all part of palliative care); reduction of stigma and discrimination; positive living.

This area is **already being monitored at the national level** in my country: **YES / NO**
IF YES,
- **Specify** which indicator(s) are being monitored (please provide full definitions, including any dis-aggregations):
- **Specify** the data collection method for each indicator:
- **Specify** data availability for each indicator (i.e., indicate the years for which data are available):
- **Specify** who provides/provided funding for data collection:
- **Specify** how this information has been **used** in for decision-making in the national AIDS program (please be as specific and detailed as possible):

IF NO,
- **Specify** the key reasons why this area is not monitored at national level:

2. Social and economic aspects:
including social protection (such as pensions, allowances, free or subsidized healthcare and school fees, child and disability benefits); targeted financial support (such as stipends, cash transfers, grants and help with funerals); income generation and employment opportunities; workplace policies and programmes; capacity building and advocacy support; food and nutrition assistance and appropriate agricultural inputs and services; clean water; transport; positive prevention; education; orphan support; adoption services; help in the home and child care.

This area is **already being monitored at the national level** in my country: **YES / NO**
IF YES,
- **Specify** which indicator(s) are being monitored (please provide full definitions, including any dis-aggregations):
- **Specify** the data collection method for each indicator:
- **Specify** data availability for each indicator (i.e., indicate the years for which data are available):
- **Specify** who provides/provided funding for data collection:
- **Specify** how this information has been **used** in for decision-making in the national AIDS program (please be as specific and detailed as possible):

IF NO,
- **Specify** the key reasons why this area is not monitored at national level:

3. Family & community aspects (more specifically defined as care for the carers):
psychosocial (including bereavement support) and medical (all part of palliative care); socio-economic and legal care and support (including prevention information). e.g., care and support needs of primary care givers which are family members or close friends who provide care and support for a PLHIV in their home, in what is often called the informal sector.

This area is **already being monitored at the national level** in my country: **YES / NO**
IF YES,
- **Specify** which indicator(s) are being monitored (please provide full definitions, including any dis-aggregations):
- **Specify** the data collection method for each indicator:

- **Specify** data availability for each indicator (i.e., indicate the years for which data are available):
- **Specify** who provides/provided funding for data collection:
- **Specify** how this information has been **used** in for decision-making in the national AIDS program (please be as specific and detailed as possible):

IF NO,

- **Specify** the key reasons why this area is not monitored at national level:

Summary of survey responses

Responses were received from the following countries/organizations:

Armenia, National Center for AIDS Prevention
Azerbaijan, UNAIDS
DRC, CORDAID
Ethiopia, Ethiopian Kale Heywot Church
Ethiopia, HIV/AIDS Management Unit, Ethiopian Civil Service College
Georgia, Infectious Diseases, AIDS and Clinical Immunology Research Center
Kenya, World Vision International
Malawi, National AIDS Commission
Malawi, MANERELA+
Namibia, Ministry of Gender Equality and Child Welfare
Nigeria, international women communication center
Republic of Moldova, PAS Center
Rwanda, Ministry of Health
South Africa, International Federation of Red Cross (IFRC)
Sudan, UNAIDS
Tanzania, Ministry of Health and social Welfare Department
Ukraine, UNAIDS
Uzbekistan, UNAIDS
Viet Nam, FHI
Yemen, UNAIDS
Zimbabwe, National AIDS Council

Key issues indicated in the responses are the following:

1. Monitoring psychosocial aspects:
- A variety of indicators is used in countries which monitor this program component.
- Countries not monitoring this program component indicated: lack of standardized indicators; lack of M&E capacity; and/or relevance of indicators only at local programmatic level as reasons.

2. Monitoring social and economic aspects:
- The majority of responding countries measure some type of economic or other external support to OVC and/or PLHIV. These data are typically collected through routine monitoring systems (i.e., not survey-based).
- Countries not monitoring this program component indicated: indicators under development; fledgling M&E systems; and/or program component not supported as reasons.

3. Monitoring family and community aspects (more specifically defined as care for the carers):
- Only one response indicated specific support provided to caregivers.
- Countries not monitoring this program component indicated: fledgling M&E systems; and/or program component not supported or not yet implemented as reasons.

Note: The full responses are available upon request.

ANNEX 2. Results from the UNGASS care and support consultation workshop

Workshop agenda

STAKEHOLDER CONSULTATION WORKSHOP: UNGASS CARE AND SUPPORT INDICATORS IN NON-CLINICAL SETTINGS

Dates: 10-11 August 2010

Venue: The Diana, Princess of Wales Memorial Fund, The County Hall, Westminster Bridge Road, London

Workshop Objectives:

1. To discuss and agree on the merits of existing UNGASS indicators in the area of HIV/AIDS care and support in non-clinical settings
2. To discuss and agree on additional and/or alternate indicators for inclusion in the UNGASS indicator set (as appropriate)
3. To discuss and agree on the rationale for the recommended UNGASS indicator selection

Workshop Outputs:

1. Consensus recommendations for UNGASS indicators in the area of HIV/AIDS care and support in non-clinical settings [Important note: *maximum* 4 quantitative indicators and a *concise number* of NCPI questions]
2. Rationale for the selected UNGASS indicators
3. Follow-up action steps

Workshop Materials:

A draft standards-based review of relevant indicators containing:

1. Purpose of the UNGASS indicators
2. Purpose of the UNGASS indicator review
3. Implications of changes to current UNGASS indicators
4. Methods for a standards-based indicator assessment
5. What should be measured related to programs and results in the area of HIV/AIDS care and support in non-clinical settings
6. Preliminary assessments of:
    a. existing UNGASS indicators in the area of care and support [UNGASS indicators 2, 10, 12]
    b. potential additional and/or alternate UNGASS indicators based on other existing care and support indicators

   These assessments will be discussed and further refined during the workshop

Tuesday, 10 August 2010		
Time	**Session**	**Presenter / Facilitator / Rapporteur**
9:00-9:30	**Registration**	
9:30-10:00	- Welcome & Participant introductions - Workshop objectives and outputs & Agenda overview - Defining HIV/AIDS care and support in non-clinical settings	UNICEF / UK Consortium on AIDS and International Development
10:00-10:30	- Purpose of the UNGASS indicator review and standards for indicator selection - Discussion / Q&A	Greet Peersman
10:30-11:00	- Global panel on monitoring experiences in the area of care and support: Current data collection processes including indicators and challenges - Discussion / Q&A	Led by UNICEF and including Global Fund, PEPFAR, UNAIDS, WFP and DHS expert
11:00-11:15	**Coffee Break**	
11:15-11:45	- Country panel on monitoring experiences in the area of care and support: Information needs and strengths & weaknesses in current data collection - Discussion / Q&A	Led by UK Consortium and including Malawi, Rwanda, Swaziland, Vietnam
11:45-12:00	- Review of existing UNGASS indicators according to agreed standards & Introduction to small group work (1) - Q&A	UNGASS Core Team
12:00-13:00	- Small group work (1): Review existing UNGASS indicators according to agreed standards	Small group work
13:00-14:00	**Lunch**	
14:00-14:30	- Small group work (1) (continued)	Small group work
14:30-15:00	- Feedback from small group work (1) (10 min/group)	Rapporteurs
15:00-15:30	- Discussion & Consensus recommendations on existing UNGASS indicators	Facilitator
15:30-15:45	- Review of short-listed existing care and support indicators according to agreed standards & Introduction to small group work (2) - Q&A	UNGASS Core Team
15:45-16:00	**Coffee Break**	
16:00-17:00	- Small group work (2): Review short-list of existing care and support indicators for potential inclusion in UNGASS indicator set (i.e., additional and/or alternate UNGASS indicators)	Small group work

Wednesday, 11 August 2010		
Time	**Session**	**Presenter / Facilitator / Rapporteur**
9:00-10:00	- Small group work (2) (continued)	Small group work
10:00-10:30	- Feedback from small group work (2) (10 min/group)	Rapporteurs
10:30-11:00	- Discussion & Consensus recommendations on additional and/or alternate UNGASS indicators	Facilitator
11:00-11:15	**Coffee Break**	
11:15-11:30	- Review of existing NCPI questions in the area of care and support according to agreed standards & Introduction to small group work (3) - Q&A	UNGASS Core Team
11:30-12:30	- Small group work (3): Review of existing NCPI questions in the area of care and support according to agreed standards	Small group work
12:30-13:00	- Feedback from small group work (3) (10 min/group)	Rapporteurs
13:00-14:00	**Lunch**	
14:00-14:30	- Discussion & Consensus recommendations on NCPI questions - Stock-taking of overall review results and remaining issues to be addressed	Facilitator
14:30-15:30	- Small group work (4): Final recommendations on quantitative indicators and NCPI questions for inclusion in UNGASS indicator set & Clear rationale for recommendations	Small group work
15:30-16:00	- Feedback from small group work (4) (10 min/group)	Rapporteurs
16:00-16:15	**Coffee Break**	
16:15-16:45	- Final consensus recommendations and rationale for UNGASS indicators in the area of care and support in non-clinical settings	Facilitator
16:15-17:00	- Next steps & Closing	UNICEF / UK Consortium on AIDS and International Development

Focus of small group work:

(1): Review existing UNGASS indicators according to agreed standards

- Discuss the preliminary assessment results and agree on any changes needed
- Agree on recommendations for continued use (or not) and/or changes to the existing UNGASS indicators

(2): Review short-list of existing care and support indicators according to agreed standards for potential inclusion in UNGASS indicator set

- Discuss the preliminary assessment results and agree on any changes needed
- Rank order the short-listed indicators according to agreed priority considerations
- Agree on the top 3 recommendations for alternate and/or additional UNGASS indicators and provide a clear rationale for each indicator and its rank

(3): Review existing NCPI questions in the area of care and support according to agreed standards

- Discuss the preliminary assessment results and agree on any changes needed
- Agree on recommendations for continued use (or not) and/or changes to the existing NCPI questions (revised, alternate and/or additional questions)
- Provide a clear rationale for the recommended changes

(4): Final recommendations on quantitative indicators and NCPI questions for inclusion in UNGASS indicator set & Clear rationale for recommendations

- Agree on the final recommendations for existing, alternate and/or additional UNGASS indicators (both quantitative indicators and NCPI questions) not exceeding 4 quantitative indicators and a concise set of NCPI questions
- Agree on the final rationale for the recommended UNGASS indicator set in the area of care and support in non-clinical settings

Any changes in UNGASS indicators should be based on and explicitly justified against the *UNAIDS 2010. Indicator Standards: Operational Guidelines for Selecting Indicators for the HIV Response. Geneva: UNAIDS/MERG (http://www.globalhivmeinfo.org/AgencySites/MERG Resources/MERG Indicator Standards _Operational Guidelines.pdf).* In line with the UNGASS Review Objectives, relevant assessment items in the *MERG Indicator Assessment Tool* were selected and applied. Note: minor adaptations in some of the statements were made to be applicable to global reporting and/or HIV/AIDS care and support programs in non-clinical settings.

Workshop participants

PARTICIPANT LIST [listed alphabetically by agency / organization]		
Name	**Agency / Organization**	**Contact details**
Bi/Multi-lateral Organizations		
1. Margaret Kugonza	Global Fund for Fighting AIDS, Tuberculosis and Malaria (Global Fund), Switzerland	Margaret.Kugonza@theglobalfund.org
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5. Priscilla Akwara*	United Nations Children's Fund (UNICEF), USA	pakwara@unicef.org
6. Rachel Yates*	UNICEF, USA	ryates@unicef.org
7. Nils Grede	World Food Program (WFP), Italy	Nils.Grede@wfp.org
Civil Society Organizations		
8. Susan Adamchak	Family Health International (FHI), USA	SAdamchak@fhi.org
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11. Liz Gwyther	Hospice and Palliative Care Association of South Africa, South Africa	liz@hpca.co.za
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13. Tetyana Salyuk	International HIV/AIDS Alliance, Ukraine	Salyuk@aidsalliance.org.ua
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16. Mike Podmore*	VSO International, UK	Mike.Podmore@vso.org.uk
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Academia		
21. Olagoke Akintola	The University of KwaZulu Natal, South Africa	Akintolao@ukzn.ac.za
Representatives for population-based surveys		
22. Kiersten Johnson	Macro Demographic and Health Surveys (DHS), USA	Kjohnson3@icfi.com
Other		
23. Greet Peersman*	Consultant (UNGASS review), Switzerland	greet_peersman@yahoo.com
24. Rod Knight	Consultant (OVC data analysis), USA	r odjknight@aol.com
Important note: The following organizations were invited but declined and/or did not propose alternates: CNLS/Rwanda, ICW/GNP+, DFID, SIDA, WB, WHO		

*UNGASS Care and Support Core Team Members (workshop organizers)

Workshop outputs

Based on preparatory work (see steps 3 and 4 explained in the review process above), draft standards-based assessments of existing UNGASS indicators and potential additional/alternate indicators for inclusion in the UNGASS set were distributed to all participants in advance of the workshop and discussed and consolidated during the workshop. The discussions focused on selection of indicators for which there are full indicator specifications and for which there is a proven track-record that they have high program relevance, and that they are feasible to collect, with reasonable cost and low data quality concerns. Consensus was reached on key recommendations for UNGASS care and support indicators and on follow-up work addressing outstanding issues and liaison with other UNGASS consultation groups.

In conclusion, the UNGASS consultation process was based on objective criteria to enable the wide range of stakeholders involved to agree on a clear and transparent rationale for the UNGASS indicator recommendations in a context in which alternative indicators exist or are under development. The Care and Support Consultation Workshop included all relevant stakeholders and reached consensus recommendations (as presented in the submission document).

ANNEX 3. Detailed indicator specifications and MERG standards-based assessment of existing UNGASS indicator 10. Percentage of orphans and vulnerable children whose households received free basic external support in caring for the child

RECOMMENDATION: This UNGASS indicator should be modified to "Proportion of eligible households who received economic support in the last 3 months"

A. REQUESTED INDICATOR INFORMATION for e*xisting UNGASS Indicator 10. Percentage of orphans and vulnerable children whose households received free basic external support in caring for the child*

Source: *Únited Nations General Assembly Special Session on HIV/AIDS. Monitoring the Declaration of Commitment on HIV/AIDS. Guidelines on Construction of core indicators. 2010 Reporting. Geneva: UNAIDS 2009.* [http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2009/20090331_UNGASS2010.asp] (p.44-45)

TITLE: Support for children affected by HIV and AIDS

As the number of orphaned and vulnerable children continues to grow, adequate support to families and communities needs to be assured. In practice, care and support for orphaned children comes from families and communities. As a foundation for this support, it is important that households are connected to additional support from external sources.

PURPOSE
To assess progress in providing support to households that are caring for orphaned and vulnerable children aged 0–17

APPLICABILITY
High HIV-prevalence countries

DATA COLLECTION FREQUENCY
Every 4 to 5 years

MEASUREMENT TOOL
Population-based surveys (Demographic Health Survey, AIDS Indicator Survey, Multiple Indicator Cluster Survey or other representative survey)

METHOD OF MEASUREMENT
After all orphaned and vulnerable children aged 0–17 in the house have been identifi ed, the household heads are asked the following four questions about the types and frequency of support received, and the primary source of the help for *each* orphan and vulnerable child. Each question is to be asked for each child.

1. Has this household received medical support, including medical care and/or medical care supplies, within the last 12 months?
2. Has this household received school-related assistance, including school fees, within the last 12 months? (This question is to be asked only of children aged 5–17.)
3. Has this household received emotional/psychological support, including counselling from a trained counsellor and/or emotional/spiritual support or companionship within the last three months?
4. Has this household received other social support, including socioeconomic support (e.g. clothing, extra food, financial support, shelter) and/or instrumental support (e.g. help with household work, training for caregivers, childcare, legal services) within the last three months?

External support is defined as free help coming from a source other than friends, family or neighbours unless they are working for a community-based group or organization.

Numerator: Number of orphaned and vulnerable children who live in households that received at least one of the four types of support for each child (answered "yes" to at least one of questions 1, 2, 3 and 4)

Denominator: Total number of orphaned and vulnerable children aged 0–17

For the purposes of this indicator and in accordance with UNICEF defi nitions (see reference below), an orphan is defi ned as a child below the age of 18 that has lost one or both parents.

A child made vulnerable by HIV is below the age of 18 and:

(i) has lost one or both parents; or

(ii) has a chronically ill parent (regardless of whether the parent lives in the same household as the child); or

(iii) lives in a household where, in the last 12 months, at least one adult died and was sick for three of the four months before he or she died; or

(iv) lives in a household where at least one adult was seriously ill for at least three of the past 12 months.

INTERPRETATION

This indicator should only be monitored in settings with high HIV prevalence (5% or greater). The indicator does not measure the needs of the household or the orphans and vulnerable children. Additional questions could be added to measure expressed needs of families caring for orphans. The indicator implicitly suggests that all households with orphans and vulnerable children need external support; some orphans and vulnerable children are more in need of external support than others. Therefore, it is important to disaggregate the information by other markers of vulnerability such as socioeconomic status of the household, dependency ratio, head of the household, etc.

If sample sizes permit, it may be useful for programmatic purposes to investigate differences between values for this indicator for orphans versus other vulnerable children. It may also be –useful to look at data disaggregated by age and duration of orphanhood, as both play a key role in determining the type of support needed. For example, an orphan whose parent(s) died 10 years ago will need support of a different kind from one whose parent(s) died within the past year.

When considering the four types of support separately, data for school-related assistance should be limited to children aged 5–17.

FURTHER INFORMATION

For further information, please consult the following website: http://www.unicef.org/aids/index_documents.html

2. MERG INDICATOR STANDARDS ASSESSMENT

1. Is the indicator fully described?

MERG Indicator Standards [MERG Indicator Standard 3] **Assessment Result: 10/14**

- *Title and definition (max 2 points):* ***1*** *[it does not have a clearly stated definition (i.e., unambiguous and/or fully defined terms) of 'external support']*
- *Purpose and rationale (max 2 points):* ***2***
- *Method of measurement (max 4 points):* ***2*** *[it does not have a well-defined measurement due to not having a clearly stated definition of 'external support']*
- *Collection method (max 1 point):* ***1***
- *Measurement frequency (max 1 point):* ***1***
- *Details of any disaggregation (max 1 point):* ***1***
- *Guidelines on how to interpret changes in the indicator (max 1 point):* ***0*** *[due to not having a clearly stated definition of 'external support']*
- *Strengths and weaknesses of the indicator (max 1 point):* ***1***
- *Additional sources of information (max 1 point):* ***1***

Maximum 14 points

Conclusion: The indicator has a high score for this Standard. It should be noted that issues raised about the definition of the indicator are mostly due to the fact that the UNGASS Guidelines do not list the specific survey questions required to construct a reliable measure. As noted above, the survey questions are extensive and standardized across DHS, AIS and MICS but have been recently removed due to key challenges noted including the time required to conduct respondent interviews.

2. How will the data from this indicator be used?

MERG Indicator Standards [MERG Indicator Standard 1] **Assessment Result: 2/11**

- *This indicator measures performance against a key international commitment, for example, MDGs, UNGASS (max 1 point):* ***1*** *[UNGASS]*
- *This indicator is relevant to some/all country contexts (max 1 point):* ***1***
- *This indicator produces information which is needed by and useful to in-country stakeholders (max 1 point):* ***0*** *[due to not having a clearly stated definition of 'external support']*
- *Information from this indicator would be helpful/essential at global/international level to distinguish performance of different countries in responding to HIV and AIDS (max 2 points):* ***0*** *[due to not having a clearly stated definition of 'external support']*
- *Information from this indicator would be helpful/essential for those managing national responses to HIV and AIDS (max 2 points):* ***0*** *[due to not having a clearly stated definition of 'external support']*
- *Information from this indicator is helpful/essential at global/international level to allow decisions to be made in terms of programme development and resource allocation (max 2 points):* ***0*** *[due to not having a clearly stated definition of 'external support']*

- *Information from this indicator is helpful/essential at national level to allow decisions to be made in terms of programme development and resource allocation (max 2 points):* ***0*** *[due to not having a clearly stated definition of 'external support']*

Maximum 11 points

Conclusion: The indicator has a very low score for this Standard. Given data use is the key impetus for collecting data, this low score is of serious concern.

3. What steps have been taken to ensure the indicator is harmonised with other indicators?

MERG Indicator Standards [MERG Indicator Standard 1] **Assessment Result: 0/5**

- *This indicator is accepted and used by all major international partners working in this technical area (max 1 point):* ***0*** *[due to having been dropped from DHS, AIS, MICS]*
- *This information is not available from other indicators (max 1 point):* ***0*** *[there are other similar indicators but with similar definitional issues]*
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding detailed description (max 1 point):* ***0***
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding systems for data collection (max 1 point):* ***0***
- *This indicator is fully harmonised with other similar indicators in the same technical field regarding time frames for data collection (max 1 point):* ***0***

Maximum 5 points

4. What process has been followed to ensure the technical value of this indicator?

MERG Indicator Standards [MERG Indicator Standard 2] **Assessment Result: 3/9**

- *The indicator is significant and important within a particular technical field (max 1 point):* ***0***
- *The indicator provides a clear and focused measure of progress in a particular technical area (max 1 point):* ***0***
- *There is a clear understanding of what changes in the value of the indicator mean, how they should be interpreted and what kind of action to take as a result (max 1 point):* ***0***
- *The indicator is sensitive to pick up small changes in performance (max 1 point):* ***0***
- *The indicator is reliable and sensitive (max 1 point):* ***0***
- *The indicator is valid and specific (max 1 point):* ***0***
- *The indicator has previously been reviewed by people with expertise in the relevant technical area (max 1 point):* ***1***
- *The indicator has previously been reviewed by people with monitoring and evaluation expertise, including particularly indicator design (max 1 point):* ***1***
- *The indicator has previously been reviewed by people with experience in a wide range of countries with different types of HIV epidemics (max 1 point):* ***1***

Maximum 9 points

Conclusion: The indicator has a very low score for this Standard. Given the requirement for *good quality* data in order to make programmatic decisions, the 0 score on critical items in this Standard, is of serious concern.

5. What evidence is there that it will be feasible to track this indicator?

MERG Indicator Standards [MERG Indicator Standard 4] **Assessment Result: 1/12**

- *The number of countries in which systems and mechanisms needed to collect data for this indicator are functioning (max 3 points): **0** [due to having been dropped from DHS, AIS, MICS]*
- *The number of countries in which systems and mechanisms needed to interpret and use data for this indicator are functioning (max 3 points): **0** [due to having been dropped from DHS, AIS, MICS]*
- *The number of countries in which this indicator is already included in national AIDS M&E systems (max 3 points): **1** [presumed those reporting on UNGASS]*
- *Evidence is presented that financial and human resources are available to measure this indicator (max 2 points): **0** [due to having been dropped from DHS, AIS, MICS]*
- *Evidence is presented that measuring this indicator is worth the cost (max 1 point): **0***

Maximum 12 points

Conclusion: Given the key data collection tools (DHS, AIS, MICS) no longer continue to measure this indicator based on key challenges indicated above, there are limited (i.e., potentially other population-based surveys) or no existing systems in place to collect it. Hence, estimates of the systems and resources required would be substantial and not worth the human and financial cost given key concerns indicated under the various Standards assessed above.

6. Where is the indicator currently being used? Where has it been field-tested?

UNGASS data availability: # countries reporting:
2004: Generalized epi: 8
Low/Concentrated epi: N/A
2006: 38 countries
2008: 38 countries
2010: 42 countries
[Note: Data across reporting periods may overlap as surveys are conducted every 3-5 years only]

Additional information on data availability from *Progress report for children affected by HIV/AIDS, UNICEF, December 2009*:
countries reporting: 24 (representing 8% of the global population)
Time period: AIS, DHS, HMIS and MICS conducted in 2005 or later
countries with two or more measurements: 0

MERG Indicator Standards [MERG Indicator Standard 5] **Assessment Result: 7/7**

- *The number of countries in which the indicator has been field-tested or used operationally*

- *The country's national program (max 3 points):* ***3*** *[presumed all those reporting on UNGASS]*
- *Countries with similar epidemics (max 2 points):* ***2*** *[those reporting on UNGASS]*
- *Other countries (max 1 point):* ***1*** *[those reporting on UNGASS]*

- *This indicator is/will be part of a global system of periodic review (max 1 point):* ***1***

Maximum 7 points

Conclusion: The indicator has a high score for this Standard. Howewer, a good score on this Standard does not weigh up against the major concerns raised through other Standards.

Summary Results

Overall score: 23/58 (40%)

Key strengths:
- programmatic relevance: Yes
- high reporting rate: Yes
- existing trend data: Yes

Key weaknesses:
- essential for decision-making: No
- quality concerns are low: No

UNGASS-related decisions:
Should the indicator be continued to be used?: No
Should the indicator be modified?: Yes
- specify modification: see below under 'Proportion of eligible households who received economic support in the last 3 months'
- does modification affect trend analysis?: Yes

Should the guidance be modified?: Yes
- specify modification: see below under 'Proportion of eligible households who received economic support in the last 3 months'

Key comments:

- Clearer guidance on defining 'external support' is needed.

- The indicator implicitly suggests that all households with OVC need external support; it is important to disaggregate by other markers of vulnerability, such as socio-economic status of the household, dependency ratio, head of household etc.

- This indicator is only focused on households with OVC. While these households are important, the indicator excludes households in need of care and support that do not have OVC. The indicator may be expanded to refer to households of people living with or affected by HIV who receive external support with disaggregation of households with/without OVC.

- In the area of social protection, there is currently a move away from targeting specific beneficiaries to targeting households; this changes the unit of measurement at program level and influences counts in population-based surveys.

- The following existing indicators with full indicator specifications were considered for modifying UNGASS indicator 10:
  1. Percentage of orphaned and vulnerable children aged 5–17 years who have three basic material needs met [source: OVC indicator manual; Global Fund]
  2. Number of eligible adults and children provided with minimum of one care service [source: PEPFAR]
  3. Number of adults and children living with HIV who receive care and support services outside facilities during the reporting period [source: Global Fund]

  Based on the standards-based assessment of each of these indicators, they were considered NOT to be viable alternatives for UNGASS indicator 10.

ANNEX 4. Modifications and MERG standards-based assessment of existing UNGASS indicator 2. National Composite Policy Index (NCPI) (sub-set of relevant questions)

RECOMMENDATION: This UNGASS indicator should be continued to be measured with minor modifications. The modifications are included in track changes below.

NCPI questions relevant to the *psychosocial* component of care and support (i.e., services including counseling services, emotional and spiritual support (all part of palliative care); reduction of stigma and discrimination; positive living.

Existing NCPI questions

PART B

1. Does the country have laws and regulations that protect ~~people~~ adults and children living with HIV and ~~/~~AIDS against discrimination? (including both general non-discrimination provisions and provisions that specifically mention HIV, focus on schooling, housing, employment, health care etc.)

   Yes *No*

   1.1 IF YES, *specify if HIV is specifically mentioned and how or if this is a general non-discrimination provision :*

   [write in]

5. Is there a mechanism to record, document and address cases of discrimination experienced by people living with HIV, most-at-risk populations and/or other vulnerable sub-populations?

   Yes *No*

   IF YES, *briefly describe this mechanism*:

   [write in]

Standards-based assessment of NCPI questions

1.1 The questions are significant and important for HIV/AIDS care and support Yes

1.2 The section provides clear and focused measures of progress towards commonly accepted goals in HIV/AIDS care and support programs; each question adds value to the intent of the section Yes

1.3 The section provides a clear picture of what needs to be done to improve the policy, strategic and legal environment for an optimal HIV/AIDS care and support program Yes

2.1 The questions are clearly phrased and terms are well-defined to avoid mis-interpretation and provide valid and reliable responses independent of the respondent Yes [with revisions as suggested]

2.2 The section is overall sensitive to picking up changes in performance, even though for some of the questions there may be saturation Yes
2.3 The section provides adequate opportunity to describe strengths and weaknesses about the responses provided No
2.4 The section provides adequate opportunity to provide clarifying examples or evidence to support the response provided Yes
3.1. Recommended changes to the NCPI require additional data collection approaches (only desk review and interviews/consultation with people knowledgeable about the topic are required) No
3.2 Recommended changes to the NCPI require substantially more time for completion of the questionnaire No

UNGASS-related decisions:
Should a question be deleted?: No
Should a question be modified?: Yes
- specify modification: Only slight modification which does not change the intent of indicator
Should a question be added?: No

NCPI questions relevant to the *human rights and legal* component of care and support (i.e., including access to legal aid, legal support and accessible legal information; human rights legislation and implementation (including violence and discrimination; land, inheritance and property rights; labor laws); succession planning, rights-based approach and rights advocacy training.

Existing NCPI questions
PART A and B

5. Does the country have non-discrimination laws or regulations which specify protections for most-at-risk populations or other vulnerable sub-populations?
Yes *No*

5.1 IF YES, for which sub-populations?

a) Women	*Yes*	*No*	
b) Young people	*Yes*	*No*	[particularly those at higher risk due to their status as children of IDU, SW, MSM]
c) Injecting drug users	*Yes*	*No*	
d) Men who have sex with men	*Yes*	*No*	
e) Sex Workers	*Yes*	*No*	
f) Prison inmates	*Yes*	*No*	
g) Migrants/mobile populations	*Yes*	*No*	
h) Other:			*[write in]*

IF YES, *briefly explain what mechanisms are in place to ensure these laws are implemented:*

[write in]

Briefly comment on the degree to which these laws are currently implemented:

[write in]

6. Does the country have laws, regulations or policies that present obstacles to effective HIV prevention, treatment, care and support for most-at-risk populations or other vulnerable sub-populations?

Yes *No*

6.1 IF YES, for which sub-populations?

a) Women	*Yes* *No*	
b) Young people	*Yes* *No*	[particularly those at higher risk due to their status as children of IDU, SW, MSM]
c) Injecting drug users	*Yes* *No*	
d) Men who have sex with men	*Yes* *No*	
e) Sex Workers	*Yes* *No*	
f) Prison inmates	*Yes* *No*	
g) Migrants/mobile populations	*Yes* *No*	
h) Other:	*[write in]*	

IF YES, *briefly describe the content of these laws, regulations or policies:*

[write in]

Briefly comment on how they pose barriers:

[write in]

Standards-based assessment of NCPI questions

1.1 The questions are significant and important for HIV/AIDS care and support Yes

1.2 The section provides clear and focused measures of progress towards commonly accepted goals in HIV/AIDS care and support programs; each question adds value to the intent of the section Yes

1.3 The section provides a clear picture of what needs to be done to improve the policy, strategic and legal environment for an optimal HIV/AIDS care and support program Yes

2.1 The questions are clearly phrased and terms are well-defined to avoid mis-interpretation and provide valid and reliable responses independent of the respondent Yes / No With revisions as suggested

2.2 The section is overall sensitive to picking up changes in performance, even though for some of the questions there may be saturation Yes

2.3 The section provides adequate opportunity to describe strengths and weaknesses about the responses provided Yes

2.4 The section provides adequate opportunity to provide clarifying examples or evidence to support the response provided Yes

3.1. Recommended changes to the NCPI require additional data collection approaches (only desk review and interviews/consultation with people knowledgeable about the topic are required) No

3.2 Recommended changes to the NCPI require substantially more time for completion of the questionnaire No

UNGASS-related decisions:
Should a question be deleted?: No
Should a question be modified?: No
- specify modification: Only slight modification which does not change the intent of indicator
Should a question be added?: No

Other NCPI questions relevant to HIV/AIDS care and support in non-clinical settings

Part A

1.3 Does the multi-sectoral strategy address the following target populations, settings and cross-cutting issues?
f. Orphans and other vulnerable children

Part A and Part B

1. Does the country have a policy or strategy to promote comprehensive HIV/AIDS treatment, care and support? (Comprehensive care includes, but is not limited to, treatment, HIV testing and counselling, psychosocial care, and home and community-based care).
Yes *No*

2. Does the country have guidelines on care and support? Yes / No
If yes, are the following included [check all that apply]:
- Psychosocial care
- Clinical care
- Social and economic support
- Human rights and legal support
- The care and support needs of carers

3. Does government provide any social transfers or support? [check all that apply]
- Pensions
- Availability of free primary health care and ART for the poor
- Free and/or subsidized educational support for poor primary and secondary school children
- Disability grants

- Child grants
- Micro-finance/credit
- Start-up kits for income generation
- Food and nutrition assistance
- Agricultural inputs

2. Has the country identified ~~the specific needs for HIV and AIDS treatment, care and support services?~~ the essential elements of a comprehensive package of HIV and AIDS treatment, care and support services?

Yes *No*

IF YES, *how were these determined?*

[write in]

IF NO, *how are HIV and AIDS treatment, care and support services being scaled-up?*

[write in]

2.1 To what extent have the following HIV and AIDS treatment, care and support services been implemented?

HIV and AIDS treatment, care and support service [NOTE: the following list is to be ordered by *Treatment and **Care and Support	The majority of people in need have access		
a. Antiretroviral therapy*	*Agree*	*Don't Agree*	*N/A*
b. Nutritional care*	*Agree*	*Don't Agree*	*N/A*
c. Paediatric AIDS treatment*	*Agree*	*Don't Agree*	*N/A*
d. Sexually transmitted infection management*	*Agree*	*Don't Agree*	*N/A*
e. Psychosocial support for people living with HIV and their families**	*Agree*	*Don't Agree*	*N/A*
f. Home-based and community-based care**	*Agree*	*Don't Agree*	*N/A*
g. Palliative care**	*Agree*	*Don't Agree*	*N/A*
h. ~~and~~ Ttreatment of common HIV-related infections*			
h. HIV testing and counselling for TB patients*	*Agree*	*Don't Agree*	*N/A*
i. TB screening for HIV-infected people*	*Agree*	*Don't Agree*	*N/A*
j. TB preventive therapy for HIV-infected people*	*Agree*	*Don't Agree*	*N/A*

k. TB infection control in HIV treatment and care facilities* Agree Don't Agree N/A

l. Cotrimoxazole prophylaxis in HIV-infected people* Agree Don't Agree N/A

m. Post-exposure prophylaxis (e.g., occupational exposures to HIV, rape)* Agree Don't Agree N/A

n. HIV treatment services in the workplace or treatment referral systems through the workplace* Agree Don't Agree N/A

o. HIV care and support in the workplace (including alternative working arrangements)** Agree Don't Agree N/A

Additions:

- early infant diagnosis*
- PMTCT, including responding to new WHO guidelines on ARV provision to pregnant women, continuing post-delivery and for infants*
- Pre-ART package for PLHIV who are not yet eligible for ART*
- ART referral and follow-up*
- Socioeconomic support**

p. Other programmes: [write in]

5. Does the country have a policy or strategy to address the additional HIV/AIDS-related needs of orphans and other vulnerable children (OVC)?

Yes No N/A

5.1 IF YES, is there an operational definition for OVC in the country?

Yes No

5.2 IF YES, does the country have a national action plan specifically for OVC?

Yes No

5.3 IF YES, does the country have an estimate of OVC being reached by existing interventions?

Yes No

IF YES, what percentage of OVC is being reached? % *[write in]*

Overall, how would you rate the efforts to meet the needs of orphans and other vulnerable children in 201209?											
201209	Very poor										Excellent
	0	1	2	3	4	5	6	7	8	9	10
Since 200997, what have been key achievements in this area: What are remaining challenges in this area:											

Standards-based assessment of NCPI questions

2.1 The questions are significant and important for HIV/AIDS care and support Yes

1.2 The section provides clear and focused measures of progress towards commonly accepted goals in HIV/AIDS care and support programs; each question adds value to the intent of the section Yes

1.3 The section provides a clear picture of what needs to be done to improve the policy, strategic and legal environment for an optimal HIV/AIDS care and support program Yes

2.1 The questions are clearly phrased and terms are well-defined to avoid mis-interpretation and provide valid and reliable responses independent of the respondent Yes [with revisions as suggested]

2.2 The section is overall sensitive to picking up changes in performance, even though for some of the questions there may be saturation Yes

2.3 The section provides adequate opportunity to describe strengths and weaknesses about the responses provided Yes

2.4 The section provides adequate opportunity to provide clarifying examples or evidence to support the response provided Yes

3.1. Recommended changes to the NCPI require additional data collection approaches (only desk review and interviews/consultation with people knowledgeable about the topic are required) No

3.2 Recommended changes to the NCPI require substantially more time for completion of the questionnaire No

UNGASS-related decisions:

Should a question be deleted?: No

Should a question be modified?: Yes

- specify modification: only slight modification which does not change the intent of indicator

Should a question be added?: Yes

- specify addition: additional questions about care and support-specific strategies & additional service elements in the care and support service listing; also note the need to order the listing under two separate headings 'Treatment' and 'Care and Support'.