

**Psychosocial Vulnerability and Resilience Measures
For National-Level Monitoring of Orphans and Other
Vulnerable Children:**

Recommendations for Revision of the UNICEF Psychological Indicator

August 12, 2006

**Report prepared for UNICEF by:
Leslie M. Snider, MD, MPH**

With support from:

**Staff of the Child, Youth, Family and Social Development Research Programme,
Human Science Research Council, South Africa**

And the Regional Psychosocial Support Initiative of Southern and Eastern Africa

Acknowledgements

The journey to development of a national-level psychological indicator has been a collaborative process over the last several years. Many colleagues have brought their insight and experience to this evolving work, and although too many to name, they are gratefully acknowledged for their contributions.

I wish to express my appreciation to the Child, Youth, Family and Social Development (CYFSD) Research Programme at the Human Science Research Council in South Africa who provided critical support during the course of this project, including office accommodation and access to African published and grey literature while the author was working on the project in Cape Town. I am deeply indebted to Professor Andy Dawes for the considerable time and effort he contributed to this project, in the midst of many other responsibilities and demands on his time. He provided valuable intellectual input, research resources and guidance and commentary on the drafts of the product as they emerged. Sincere thanks also to Dr. Cathy Ward of CYFSD and to Rene Brandt of the University of Cape Town Psychology Department for sharing the lessons of their work with at-risk children and youth, and their valuable guidance on the measures.

The Regional Psychosocial Support Initiative (REPSSI) has contributed enormously to best practices in the field of psychosocial support to orphans and vulnerable children, and has been involved in the development of national-level psychosocial indicators for UNICEF since inception. I would like to gratefully acknowledge Noreen Huni, REPSSI Executive Director, for her ongoing support, and Jonathan Morgan, Doreen Muza and Brighton Gwezera for their assistance with the qualitative field work in South Africa and Zimbabwe and their personal insights. Kind thanks to Stefan Germann, currently of World Vision, for first providing the author the opportunity to be involved in this important initiative.

My kind thanks to Lucie Cluver of Oxford University for sharing her concurrent literature review, resources and lessons from her own research. Thanks also to Paul Bolton for sharing his work with conflict-affected adolescents and unique experience in ethnographic validation of psychological measures. My thanks also to Roeland Monasch, UNICEF Zimbabwe, for his ongoing support of psychosocial research for orphans and vulnerable children in Africa, sharing of emerging findings from Zimbabwe, and for promoting the inclusion of psychosocial measurement in the UNICEF Guide.

From Tulane University School of Public Health and Tropical Medicine, special thanks to Megan Littrell, MPH, MSW, and to Whitney Fry, MPH, for their assistance with literature reviews and tracking down unpublished and grey literature for inclusion in the study.

Finally, I would like to sincerely thank Mary Mahy of UNICEF for her unique vision and support of this project and dedication to refining the measurement of psychosocial health of orphans and other vulnerable children.

Table of Contents

Overview of the Project

1. Introduction
 2. Background to Development of the Indicators
 3. Limitations in Current Approaches
 - 3.1 Reflections on the Current Psychosocial Indicators
 - 3.2 Resilience and Vulnerability in the Context of HIV/AIDS
 - 3.3 The “OVC” Construct
 4. Psychosocial Perspectives on the Experience of Children at Risk: What is Particular to OVC?
 - 4.1 HIV/AIDS, Poverty and Psychosocial Health
 - 4.2 The Experience of Death, Loss and Grieving for AIDs-Affected Children
 - 4.3 Stigma and Discrimination of HIV/AIDS-Affected Children
 - 4.4 Increased Risk of Infection in HIV/AIDS-Affected Children
 5. Africa-Based Literature and Instrument Review: Discussion of Findings
 - 5.1 Methodologic Limitations in Africa-Based Research
 - 5.2 Challenges in Assessing Psychosocial Well-being in Developing Country Settings
 - 5.3 Africa-Based Review: Methods and Findings
 - 5.3.1 Summary of findings from surveys utilizing control/comparison groups
 - 5.3.2 Other surveys of OVC
 - 5.3.3 Psychosocial surveys of adolescents exposed to violence/war
 - 5.3.4 Qualitative and descriptive studies
 6. Key Domains and Instrument Recommendations for Psychosocial Measures of Vulnerability~Resilience
 - 6.1 Caregiver Instrument: Domains, Rationale and Suggested Items
 - 6.2 Youth Instrument: Domains Rationale and Suggested Items
 7. Conclusion
- Appendix A: Table: Review of Africa-Based Research
Appendix B: Findings from Focus Groups

Psychosocial Vulnerability and Resilience Measures for National-Level Monitoring of Orphans and Other Vulnerable Children

Overview

Based on expert consultations to the psychosocial indicators developed for UNICEF *Guide to Monitoring and Evaluation of the National Response for Children Orphaned and Made Vulnerable by HIV/AIDS*, a process was proposed to refine psychosocial measurement through population-based surveys and national-level indicator development.

This activity is designed to support such an initiative. It provides a literature and instrument review, building on the preliminary review of studies and instruments compiled for the UNICEF NY technical consultation in July 2005. The review focuses on Africa in particular, adding additional evidence for evaluation methods and theoretical frameworks for vulnerability, resilience and psychosocial well-being and measurement approaches from resource-poor settings. The overall goal is to produce a concise, directed instrument, drawing as far as possible on existing validated instruments, to capture the critical aspects of psychosocial vulnerability and resilience among children in different countries and cultural contexts for monitoring on a national level.

The output for this activity is a set of recommendations for a draft psychosocial vulnerability~resilience instrument for purposes of national-level monitoring of the situation of children affected by HIV/AIDS. The present contribution provides instruments for caregivers and adolescents that tap a set of core domains for assessing household, community and personal measures of youth vulnerability, resilience and psychosocial outcomes. Whether or not data derived from the instrument domains can be combined to provide a single vulnerability~resilience indicator will depend upon empirical investigation subsequent to the establishment of validity and reliability of the measures.

Following from the current activity, a process for testing and validation of the instrument is proposed which includes:

1. Qualitative Study: Recognizing that constructs of emotional and social well-being are grounded in culture, a community level, qualitative study to capture local descriptions for informing development of the vulnerability-resilience indicator. The instrument provided here has been assessed in focus groups with two southern African communities; however, this is not sufficient. We suggest further qualitative work of this nature be undertaken in other African societies before the tool is finalized.
2. Development and Pilot Testing: Pilot testing of this instrument in at least two sub-Saharan African countries (in at least four ethno-linguistic communities) in order to establish its validity (face, construct and discriminant) and reliability.

This work is the product of a collaboration between Dr. Leslie Snider (the project consultant) and UNICEF, with input from the staff of the Child, Youth, Family and Social Development (CYFSD) research programme of the Human Science Research Council (HSRC). The Regional Psychosocial Support Initiative (REPSSI) has been involved in the process of psychosocial indicator development from inception and provided assistance in the current project. Collaboration with leading African researchers and psychosocial experts has helped to enhance the cultural and context relevance of the measures and provided access to sites for focus groups.

1. Introduction

Among the international promises made to children orphaned and made vulnerable by HIV/AIDS, is a commitment to:

*“...implement national policies and strategies to build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS, including by providing appropriate counseling and psychosocial support; ensuring their enrolment in school and access to shelter, good nutrition and health and social services on an equal basis with other children; and protect orphaned and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance...”*¹

The UNGASS Declaration of Commitment (UNGASS DoC, paragraph65) states that signatory countries will:

*“...by 2003 develop (and by 2005 implement) strategies to strengthen government, family and community capacities to provide a supportive environment for orphans and girls and boys affected by HIV/AIDS with counseling, support, schooling, nutrition and services.”*²

As part of this exercise and in terms of reporting requirements, governments are required to monitor the situation of children affected by HIV and AIDS. The UNAIDS, UNICEF, USAID, WFP Rapid Assessment, Analysis and Action Planning on Children Orphaned and Made Vulnerable by HIV/AIDS carried out in 2004 (known as the OVC RAAAP exercise) revealed the need for good data on this group.

Furthermore, the United Nations Convention on the Rights of the Child (UN CRC), in Article 44, commits signatories to report on the situation of children every five years to the Committee on the Rights of the Child. The Committee requires that children in vulnerable circumstances receive attention in the reports. It is therefore appropriate that attention is given to development of sound measures of the situation and well-being of orphans and children affected by AIDS.

¹ United Nations. Declaration of Commitment on HIV/AIDS. United Nations General Assembly Special Session on HIV/AIDS. New York, 25-27 June 2001, p. 29.

² United Nations. A World Fit for Children. United Nations General Assembly Special Session on Children. New York, 8-10 May 2002.

In February 2005, UNICEF published the *Guide to Monitoring and Evaluation of the National Response for Children Orphaned and Made Vulnerable by HIV/AIDS*, a collaborative effort of a large number of individuals and agencies. National-level indicators were developed for this guide in order to measure progress of governments and other key stakeholders in implementing the 2001 UN Declaration of Commitment strategies and Millenium Development Goals. The Guide provides methods and tools for monitoring the effectiveness of national responses to children thereby informing programming and policy, and supplements the UNGASS/AIDS and MDG “orphan school attendance indicator” with a set of recommended standardized indicators in broader domains.

The UNICEF Guide has ten domains which need to be monitored at the national level. (see Figure 1 below.) The set is necessarily very limited and does not cover a range of consequences of the epidemic on children, households and communities. Specific studies are required to explore the situation in more depth. It is also important to distinguish between high-level indicators for monitoring the prevalence, situation and services available to children affected by HIV/AIDS, and those needed to monitor the outcomes of particular programmes and policies.

Figure 1: UNICEF Indicators for orphans and other children made vulnerable by HIV/AIDS

Strategic Approach	Age	Key Domains	Measurement Tool
Strengthening the capacity of families to protect and care for children			
<i>Core indicators</i>			
1: Basic material needs	5–17	Family capacity	Population-based survey
2: Malnutrition/underweight prevalence	0–4	Food security and nutrition	Population-based survey
3: Sex before age 15	15–17	Health	Population-based survey
<i>Additional indicators</i>			
A1: Food security	NA	Food security and nutrition	Household survey
A2: Psychological health	12–17	Psychosocial	Population-based survey
A3: Connection with an adult caregiver	12–17	Psychosocial	Population-based survey
A4: Succession planning	NA	Protection	Household survey
Mobilizing and strengthening community-based responses			
<i>Core indicators</i>			
4: Children outside of family care	0–17	Institutional care and shelter	Street children survey and institution survey
5: External support for orphaned and vulnerable children	0–17	Community capacity	Household survey
<i>Additional indicator</i>			
A5: Orphans living with siblings	0–17	Community and	Population-based survey

		family capacity	
Ensuring access to essential services			
<i>Core indicators</i>			
6: Orphan school attendance ratio	10–14	Education	Population-based survey
7: Birth registration	0–4	Protection	Population-based survey
Ensuring that governments protect the most vulnerable children			
<i>Core indicator</i>			
8: Orphaned and Vulnerable Children Policy and Planning Effort Index	NA	Policies/strategies, resources and resource mobilization	Key informant interviews
<i>Additional indicator</i>			
A6: Property dispossession	15–49	Protection	Household survey
Raising awareness to create a supportive environment			
<i>Core indicators</i>			
9: Percentage of children who are orphans	0–17	Policies/strategies	Population-based survey
10: Percentage of children who are vulnerable	0–17	Policies/strategies	Population-based survey
<i>Additional indicator</i>			
A7: Stigma and discrimination	15–49	Protection	Population-based survey

Source: UNICEF³

As is evident in the figure, and as part of the commitment to ensuring that children’s psychosocial support needs are met, the Guide includes two additional indicators under the strategic approach strategy of strengthening the capacity of families to protect and care for children. They are:

1. Connection with an adult caregiver (A3)
2. Psychological health (A2)

Psychosocial well-being of children is recognized as essential to ensuring their healthy growth and development, and the ability to achieve their full potential. However, measurement of psychosocial well-being, especially at a national-level for children in difficult circumstances, has few tested and established precedents.

This contribution seeks to take this process forward, building on the lessons from an ongoing expert consultation to the psychosocial indicators, including a preliminary literature and survey review for the UNICEF NY technical consultation in July 2005. It provides reflection upon the conceptualization, national-level evaluation methods and theoretical frameworks for vulnerability, resilience and psychosocial well-being of children from resource-poor settings such as sub-Saharan Africa, focusing particularly on Africa-based studies and literature.

³ UNICEF (February 2005) Guide to monitoring and evaluation of the national response for children orphaned and made vulnerable by HIV/AIDS. New York.

This reflection has led to an elaboration on the original work for the following reasons:

1. Conceptual and cross-cultural limitations of solely measuring “psychological health” based on piloting of the original indicator.
2. Acknowledgement of the difficulty in discriminating the experience of HIV/AIDS-affected children from all children living in compromised environments.
3. The need to encompass an understanding of the multi-dimensional nature of personal and contextual psychosocial risk and resilience factors.
4. The value in focusing that multi-dimensional understanding on a limited number of critical measures of risk factors and psychosocial functioning, namely children’s capacity for surviving and thriving in contexts of multiple risk.

Measures of psychosocial vulnerability and resilience in key domains are therefore proposed to encompass the critical areas of psychological well-being, resilience and social inclusion for at-risk children in order to monitor, at a national-level, their status on a continuum from surviving to thriving. Risks to children’s well-being evolve through the life journey, as do their strengths and capabilities for navigating and managing new challenges. The distribution of children in the country along this continuum at any point in time provides an understanding of the internal and contextual risk and resilience factors affecting their well-being, which are influenced by national responses, programs and policies for children affected by HIV/AIDS. This is consistent with recommendations for monitoring and research on strategic issues that ensure interventions make a difference in the lives of children and families, including development of “child and community vulnerability indices to use in mapping and setting geographic priorities for interventions.”⁴

The consultative process of refinement of the original indicators is outlined below, in addition to a review of existing theoretical frameworks and literature on Africa-based studies and instruments. This paper also critically examines the approach and assumptive definitions to national-level evaluation of the response for “children orphaned and made vulnerable by HIV/AIDS.”

2. Background to Development of the Psychosocial Indicators: Consultative Process

Few models exist to inform development of a national-level psychosocial indicator, given that psychosocial monitoring and evaluation strategies remain in their infancy and standards have not yet been developed to guide programs or assessments. The original indicator suggested in Gabarone 2001 was:

⁴ Williamson, J. (2005) Finding a way forward: Reducing the impacts of HIV/AIDS on vulnerable children and families. *A Generation at Risk: The Global Impact of HIV/AIDS on Orphans and Vulnerable Children*. Foster, Levine & Williamson (eds.) Cambridge University Press: New York.

“The percentage of orphans participating at least monthly in organized group activities which address ‘appropriate psychosocial support.’”⁵

However, this indicator was limited in three main ways:

1. Its focus solely on formal support sources and not the myriad informal sources of support children access and utilize;
2. The fact that participation in formal psychosocial support activities does not guarantee effectiveness as programs vary widely in their quality and components, and;
3. Such “low dose” exposure (once a month) is unlikely to have significant positive benefits for children at risk of psychosocial difficulties.

In addition, national strategies intend to strengthen family and community capacity to create a positive environment for the care and protection of children, which may include but are not limited to formal psychosocial support services.

The UNICEF psychosocial indicators for OVC were designed to approximate the status of children in relation to their psychological health and connectedness to a primary adult caregiver. They were created to be included in *brief, quantitative surveys* to tap constructs relevant to all children, regardless of language and culture, and to articulate broad domains of child well-being (emotional/cognitive, functioning, behavior and social connectedness and capacity).

This was an innovative approach with significant challenges; thus, the indicators were developed as *work in progress* and received ongoing expert consultation in their refinement and validation. This process included pilot testing in conjunction with other indicators in Kingston, Jamaica and Blantyre, Malawi in 2004 and other expert consultations. Results of those processes included the following:

- Pilot testing revealed the following findings and recommendations:
 - The majority of questions for the psychological indicator were understood and provided an opportunity for respondents to talk about their experience, according to interviewers in Jamaica.
 - There was some difficulty with specific items – “feeling happy” (time frame may not have been specified, term may be too broad or imprecise) and “being alone” (may represent a positive coping strategy rather than evidence of isolation) – as well as difficulty for respondents in understanding of response scales.
 - Recommendations included use of resilience measures, replacing mood with life satisfaction items and pictorial or binary response scales. Recommendations were incorporated into the published version of the psychological indicator, and the need for validation of terms in the local context and language was emphasized in the instructions.

⁵ UNAIDS and UNICEF. Report on the Technical Consultation on Indicators Development for Children Orphaned and Made Vulnerable by HIV/AIDS, Gabarone, Botswana 2-4 April 2003.

- Pilot testing of the connection indicator noted that 1) it is solely focused on relationship with one primary caregiver and does not address peer relationships and other sources of adult support, 2) some items may be biased by cultural beliefs and practices around child-rearing, and 3) difficulties with understanding response scales (similar to the psychological indicator).
- Expert consultation through a meeting hosted in Cape Town in April 2005 by the Bernard van Leer Foundation produced similar responses to the connection indicator, and the following recommendations for the psychological indicator were made:
 - Reduce the number of questions and simplify the domains of psychological well-being that frame them. Consider deleting items that pertain to mood, functioning/capability and externalizing/internalizing behaviors. Retain items related to stress/worry, life satisfaction, future orientation and hopefulness, self-esteem or self-worth and self-perception of physical health.
 - Conduct a strong literature review and validation study for the indicator.
- A UNICEF consultation in July 2005 provided the following recommendations:
 - Three indicators are proposed to best capture psychosocial well-being: a) psychological health, b) connectedness to an adult in the child's life and c) social inclusion into the larger community network.
 - A theoretical framework is necessary to conceptualize, develop and validate psychosocial indicators and may be drawn from existing theories related to child development, resilience and levels of life needs.
 - In addition to the original domains of well-being, it was suggested that thoughts and feelings of children in crises may potentially be captured by direct and practical questions about survival. Relevant challenges are the child's sense of fear, lack of personal safety and need to rely on inner personal resources in an environment that does not provide adequate safety and care.
 - Items and domains should be informed by the way children themselves assess their psychosocial well-being or distress.
 - There is a need for triangulation of data through child and caregiver reports and direct observation, if possible.
 - It is important to keep a perspective of child well-being beyond the individual child to understanding the elements of resilient communities that provide an enabling environment for their growth and development.

The connection indicator is currently undergoing regional pilot testing through a WHO initiative. The activities outlined in this contribution therefore pertain to the incorporation of the suggested psychological health and social inclusion indicators into the new “vulnerability-resilience measure.”

In developing an appropriate vulnerability~resilience measure, we examine below the psychosocial experience of children at risk based on our understanding of life challenges for children affected by HIV/AIDS as well as the underlying contexts of poverty and

disadvantage for all children in resource-poor settings. Within this review is a critical analysis of the definitions we have developed for targeting the “most vulnerable” and the difficulties in discriminating OVC from other children in enduringly difficult circumstances.

3. Limitations in Current Approaches

3.1 Reflections on the Current Psychosocial Indicators

Important lessons from the consultative process outlined above included limitations in understanding the actual experience of children and their capacity for coping through the use of Western psychological scales. Items drawn from standardized depression or anxiety scales are often adapted for use in developing country settings. However, even with translations and adaptations of terms, cultural and linguistic differences make it difficult to know whether or not questions related to emotions are understood by respondents and if they truly reflect local understandings of emotional well-being and distress. Norms for the expression of internalizing and externalizing behavior also influence the understanding of respondents to standardized questions and their endorsement of particular items in different cultures. Stigmatization around mental illness may also influence the sensitivity of questions for respondents and how they choose to answer them.

Adolescence is itself a cultural construct, and the period may manifest differently in modern Westernized contexts and rural peasant environments. In the modern West at least, it is seen as a time of emotional upheaval and understanding of a new range of emotional, physical and social experience in the transition to adulthood. However, cultural expectations for behavior, responsibilities and capacities of children and adolescents may differ substantially in non-Western societies, where young people may take on responsibilities for care of younger siblings, household chores, livelihood contributions and other tasks at early ages. Adolescence as the transition to adulthood in some cultures may reflect expectations for self-sufficiency and autonomy quite different from Western norms. For example, as described by Gillian Mann, Somali boys as young as age 12 from traditional, nomadic pastoral peoples may be expected to spend several months away from the family tending herds and relying on their peers for practical and emotional support.⁶ Thus, “childhood,” “adolescence” and even “family” may mean very different things in different cultural contexts.

Although the current psychological indicator has instructions for translation, adaptation and validation in different languages and contexts, it is possible that items may undergo significant changes making it difficult to interpret and compare children’s well-being outcomes solely on the basis of emotional/behavioral measures. As stated by Forehand, in addition to establishing the relationship between orphaning and psychological distress, we also need to identify personal and contextual aspects that enhance resilience and which can be targeted in interventions.⁷ A true picture at a national level of children’s vulnerability and resilience must therefore encompass a measurement of risk exposure as well as social, cognitive and emotional competence in facing life’s challenges

⁶ Mann, G. (2001) Networks of Support: A Literature Review for Separated Children. Save the Children Sweden.

⁷ Forehand, R., Steele, R., Armistead, L., Morse, E., Simon, P. and Clark, L. (1998) The Family Health Project: Psychosocial adjustment of children whose mothers are HIV infected. *Journal of Consulting and Clinical Psychology*, 66: 513-20.

successfully. Contextual factors would include exposure to abuse and exploitation, as well as the experience of social inclusion or exclusion.

Measures of these contextual factors are captured currently in the Guide through the following core and additional indicators:

1. connection to a primary caregiver
2. family capacity to protect and care for children
3. community-based responses
4. access to essential services
5. governmental protection of the most vulnerable children
6. awareness of supportive environments

These can be considered proxy measures for social inclusion and exclusion – a critical aspect of the context of children affected by AIDS. However, some important gaps exist in information captured by these indicators that would be valuable to include in a revised survey instrument. For example, the experience of social inclusion to community, peers and other significant adults is currently not adequately captured in the existing psychosocial indicators. From a developmental perspective, an accurate assessment of critical connections in the social world of adolescents extends beyond their connection to a primary caregiver. As documented earlier, many HIV/AIDS affected adolescents are themselves heads of households, and living without any adult supervision or guidance. The well-being of OVC, including youth-headed households, ultimately depends upon the ability of the community to create a protective and nurturing environment for their growth and development.

For adolescents in difficult circumstances, the capacity to assess, recognize and mobilize social support from different quarters may be critical to their achieving a reasonable quality of life. As Wild et al.⁸ point out, the protective effects of social relationships for adolescents are differentially related to the variety of social contexts in their lives, including peers, school and neighborhood, in addition to the parent-child relationship, and deficits in the family relationship can be compensated by positive relationships in other social spheres.⁹ Peer relationships fulfill critical psychosocial and development needs for youth,¹⁰ and along with the availability of caring adults (for example through formal or informal mentorship), promote resilience.¹¹

The experience of social inclusion and exclusion are reflections of a critical factor in psychosocial well-being outcomes for adolescents affected by HIV/AIDS: stigma. Stigma is perhaps the most significant aspect particular to HIV/AIDS orphans and their

⁸ Wild, L., Flisher, A., Laas, S. and Robertson, B. (2006) The Psychosocial adjustment of adolescents orphaned in the context of HIV/AIDS. University of Cape Town (in press).

⁹ Barber, B.K. & Olsen, J.A. (1997) Socialization in context: connection, regulation and autonomy in the family, school and neighborhood and with peers. *Journal of Adolescent Research*, 12: 287-315.

¹⁰ Ledward, A. and Mann, G. (2000) The best interests of 'separated' children in Rwanda. *Cultural Survival Quarterly*, 24 (2).

¹¹ Masten, A.S., & Coatsworth, J.D. (1998). The development of competence in favorable and unfavorable environments. Lessons from research on successful children. *American Psychologist*, 53(2): 205-20.

psychosocial outcomes.¹² Stigma is currently measured in the UNICEF instrument through four questions administered as a general population survey assessing attitudes toward people with HIV, and provides a general indication of stigma in the community. However, and most importantly, it does not provide a measure of the exposure of adolescents to stigma, discrimination, abuse and exploitation which have direct impacts on psychosocial outcomes.

3.2. Resilience and Vulnerability in the Context of HIV/AIDS

The concept of resilience emerged in the psychiatric literature in the 1980's, in an attempt to understand individual differences in people's responses to stress and adversity. Child development studies at the time used the concept in understanding why only some children at major risk (by virtue of having seriously mentally ill parents or growing up in poverty) developed significant psychopathology or other impairments in childhood or later in adulthood.¹³ The idea emerged that certain "salutogenic" (protective) and "pathogenic" (risk) factors influenced outcomes; in other words, personal and social conditions that increase, or diminish the likelihood of the child developing problem behaviors.¹⁴

Personal resilience factors have been variously defined in the literature. For example, in their UNICEF Review article Apfel and Simon define resilience as the "capacity to bounce back from traumatic childhood events (including exposure to war) and develop into a sane, integrated and socially responsible adult." They describe resilient children according to their: resourcefulness, curiosity and intellectual mastery (ability to conceptualize), flexibility in emotional experience, access to autobiographical memory (including the ability to remember and invoke images of warm and loving people in their lives), a goal for which to live, altruism ("learned helpfulness") and a vision of a moral order.¹⁵ Rutter identifies three characteristics of a person demonstrating resilience:¹⁶

1. A sense of self-esteem and self-confidence
2. A sense of self-efficacy (belief in their capacity to make a difference)
3. A repertoire of social problem-solving approaches

¹² Stein (2003)

¹³ Evans, R. (2005) Social networks, migration and care in Tanzania: Caregiver's and children's resilience to coping with HIV/AIDS. *Journal of Children and Poverty*, 11 (2): 111-29.

¹⁴ Antonovsky (1987) *Unraveling the mystery of health: How people manage stress and stay well*. San Francisco: Jossey and Boss.

¹⁵ Apfel, R. and Simon, B. (1995) On psychosocial interventions for children: Some minders and reminders. UNICEF Review Paper for the *Conference on Psychosocial Interventions*, Cambridge, MA.

¹⁶ Rutter, M. (1985) Resilience in the face of adversity: Protective factors and resistance to psychiatric disorder. *British Journal of Psychiatry*, 147: 598-611.

Similarly, Lerner identifies five positive developmental outcomes for children which can enhance civil society and improve transgenerational transmission of resilience.¹⁷ These are summarized by the “5 C’s” or five clusters of individual attributes:

1. Competence (intellectual ability, social and behavioral skills)
2. Connection (positive bonds with people and institutions)
3. Character (integrity and moral centeredness)
4. Confidence (positive self-regard, sense of self-efficacy, courage)
5. Caring/Compassion (human values, empathy, a sense of social justice)

Masten & Coatsworth provide the following definition of resilience: “manifested competence in the context of significant challenges to adaptation or development.”¹⁸ These individual attributes of “resilient” children – sometimes termed universal protective factors¹⁹ - must also be combined with supportive features of the child’s environment in order to help children overcome adversity and proceed on a positive life course. Individuals take an active role in engaging with protective factors in the environment, in addition to innate assets in their personality. The effective use of protective factors and resources depends on the ability of the individual to creatively interact with and utilize resources.²⁰ For example, resilient children are able to capitalize on their assets, such as good interpersonal skills and the ability to engage others, in order to gain social and other support.²¹ This discourse has therefore led not only to a shift in emphasis in psychiatric research from vulnerability to resilience, but also from a focus on risk variables to the *process* of negotiating risk situations.

Despite adverse conditions, the literature shows that children affected by HIV/AIDS demonstrate positive agency in negotiating challenges their lives and ability to access emotional support from available sources. In her qualitative study of impacts of HIV/AIDS on children and families in northern Tanzania, Evans found that the epidemic is exacerbating poverty, social marginalization and gender inequalities among poor families, with particular risk to female and child-headed households. Critical to survival of female-headed households were women’s social networks, which included an ability to move between rural and urban areas to care for children and sick and dying relatives. Children expressed their resilience by taking on responsibility for daily tasks and survival needs of the household. Important sources of emotional support for them were relationships with siblings and other surviving members of the household. In addition, some children who were ostracized by their families coped by migrating to the city, and demonstrated considerable resilience in meeting their needs including developing social important peer networks. However, those living on the street remained at considerable

¹⁷ Lerner, R., Fisher, C. and Weinberg, R. (2000) Toward a science for and of the people: Promoting civil society through the application of developmental science. *Child Development*, 71 (1): 11-20.

¹⁸ Masten, A. & Coatsworth, J. (1998) The development of competence in favorable and unfavorable environments: Lessons from research on successful children. *American Psychologist*, 53 (2): 205-20.

¹⁹ Luthar, S. S., Cicchetti, D. & Becker, B. (2000) The construct of resilience: A critical evaluation and guidelines for future work. *Child Development*, 71 (3): 543-62.

²⁰ Rutter (1985)

²¹ Werner, E. (2000) Protective factors and individual resilience. In J. P. Shonkoff & S. J. Meisels (Eds.), *Handbook of Early Childhood Intervention (2nd Edition)* (pp. 115-132). Cambridge University Press.

risk of HIV infection.²² Likewise, Foster reports that children heading households demonstrate resilience in developing a range of coping strategies to meet their basic needs.²³

In terms of environmental factors, characteristics of families and aspects of the wider social contexts are important as risk and protective factors.²⁴ Within families and communities, protective factors may include the child's stable and close relationship with an authoritative primary caregiver, relationship with siblings, a supportive extended family network, peer friendships, positive school experiences, opportunities to engage in social life (including pro-social organizations and a religious faith community) and access to quality services and institutions such as well-functioning schools.^{25 26 27} In HIV/AIDS affected households, sibling relationships may take on added importance as a source of emotional support, and may be a particular coping strategy in child-headed households.

The continual interplay between intra-personal and environmental protective factors underlies the dynamic concept of resilience.²⁸ As Atwine et al explain, resilience and vulnerability are not "single, linear concepts."²⁹ Protective factors may mediate some aspects of psychosocial outcomes and not others. For example, a study of orphans in Uganda who had access to peer support groups (contact with other orphans) were predictive of higher levels of self-concept but not lower levels of internalizing problems (anxiety or depression). Thus, support groups may reduce shame and stigma through peer connections, but did not seem to mediate internalizing distress.³⁰

In addition, risks may alter as circumstances change in families and social systems, and resilience may be evident in one domain (school) but not in another (family). Just as several dimensions of vulnerability in the household and community may affect psychosocial outcomes, the type of adversity or risk the child is exposed to, its severity and chronicity, may also be important. Resilient "outcomes" may therefore need to be defined in terms of exposure to particular adverse conditions.³¹

3.3 The "OVC" Construct

²² Evans (2005)

²³ Foster, G., Makufa, C., Drew, R. and Kralovec, E. (1997) Factors leading to the establishment of child-headed households: The case of Zimbabwe. *Health Transition Review*, 7 (2): 155-68.

²⁴ Masten, A., Best, K. and Garmezy, N. (1990) Resilience and development: Contributions from the study of children who overcome adversity. *Development and Psychopathology*, 2: 425-44.

²⁵ Ibid.

²⁶ Luthar et al (2000)

²⁷ Gilligan, R. (2000) Adversity, resilience and young people: The protective value of positive school and spare time experiences. *Children and Society*, 14 (1): 37-47.

²⁸ Luthar et al (2000)

²⁹ Atwine, B., Cantor-Graae, E., Bajunirwe, F. (2005) Psychological distress among AIDS orphans in rural Uganda. *Social Science and Medicine*, 61: 555-64.

³⁰ Ibid.

³¹ Luthar et al (2000)

A sticking point in the discourse on vulnerability and resilience for children affected by AIDS is the “OVC” construct. Services and resources for children affected by AIDS were initially focused on care for orphans. However, this excluded other vulnerable children, including those living with a sick caregiver and children living in extreme poverty. The differential treatment of orphans in some support programs has caused jealousies and inequities over distribution of resources at the community level. As Foster and Williamson point out, “it is difficult, and indeed inappropriate, to determine eligibility for assistance on the basis of the specific cause of parental death.”³²

The Oxford English dictionary provides the following definitions of “orphans”: 1) without parents or bereaved, and 2) one bereft of protection, advantages, benefits or happiness previously enjoyed. Citing Foster and Williamson (2000), Bray notes that the word for orphan in many African languages likewise refers to a child who is destitute or without care, rather than parentless, and in Zambia would exclude children living with an adult relative.³³ Giese et al also note that in their research, participants frequently understood “orphans” to be children living in poverty, whether or not their biological parents were alive. They suggest that severe poverty is a more appropriate indicator of vulnerability than orphan status alone. Since “not all children who experience orphanhood are vulnerable” and many non-orphaned children in the community were equally vulnerable to the orphans receiving services, she suggests that local people must be involved in identifying the most vulnerable children within a context.³⁴

Determining the actual numbers of orphans, as well as a definition of orphans, may also be problematic.³⁵ Bray draws attention to exaggerations of numbers of orphans by media³⁶ and similar errors over the last two decades made by various development bodies (UNICEF, ILO and others) in estimating numbers of street children.³⁷ In addition, it is rare that baseline estimates of orphaning prior to the pandemic are used for comparison to current AIDS orphan estimates.³⁸ In contrast, she also cites Monk who warns that definitions of orphans, such as that used by UNAIDS which is limited to maternal orphans under age 15, may underestimate the problem by excluding many children

³² Foster, G. and Williamson, J. (2000) A review of the current literature on the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS*, 4 (4): 275-84.

³³ Bray, R. (2003) Predicting the social consequences of orphanhood in South Africa. Centre for Social Science Research, Social Surveys Unit, University of Cape Town, CSSR Working Paper No. 29.

³⁴ Giese, S., Meintjes, H., Croke, R. And Chamberlain, R. (2003) Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS: Research report and recommendations. Submitted to National Departments of health and Social Development by *Children's Institute*, University of Capetown.

³⁵ Bray (2003)

³⁶ Hunter, S. (1990) Orphans as a window on the AIDS epidemic in Sub-Saharan Africa: Initial results and implications of a study in Uganda. *Social Science and Medicine*, 31 (6): 681-90.

³⁷ Connolly, M. and Ennew, J. (1996) Introduction: Children out of place. *Childhood*, 3 (2): 131-45.

³⁸ Ennew, J. (2001) Dead parents or absent parents: Who is defining orphans in the twenty-first century? Some reflections on policies for orphans in Sub-Saharan Africa and South East Asia. Notes toward a presentation at the *Conference on 'Orphans and Vulnerable Children in Africa,'* University of Uppsala.

seriously impacted by the pandemic (i.e., paternal orphans, or adolescents orphaned over age 15, as well as children living in households who have fostered orphans).³⁹

Finally, socio-political factors may also be important in determining children's orphan and vulnerability status, as well as their experience of risk and protective factors in the social context. In the Rwanda study of youth-headed households, a percentage of children were "functionally" rather than "biologically" orphans. The majority of parents died due to "illness or poison" which local experts say could reflect death due to AIDS, suicide or actual poisoning by community members following the genocide. In addition, 3.6% of fathers were reportedly in jail, some accused of perpetrating genocide. The sources of orphanhood and vulnerability for these children reflect a high level of social disruption and mistrust, and are reflected in the high rates of social marginalization they report. The authors therefore advise avoiding broad generalizations of orphans and care practices, and rather to consider how support of orphans varies given each community's particular political and socio-economic context.⁴⁰

³⁹Monk, N. (2000) Underestimating the magnitude of a mature crisis: Dynamics of orphaning and fostering in Uganda. *Orphan Alert: International Perspectives on Children Left Behind by HIV/AIDS*. Association Francois-Xavier Bagnaud.

⁴⁰ Thurman, T. Snider, L., Boris, N., Kalisa, E., Mugarira, E., Ntaginara, J., and Brown, L. (2006) Psychosocial support and marginalization of youth-headed households in Rwanda. *AIDS Care*, 18 (3): 220-29.

4. Psychosocial Perspectives on the Experience of Children at Risk: What is Particular to OVC?

The sheer scale of the HIV/AIDS pandemic with its progressive impacts on children and families is the basis for targeted funds, policies and national strategies. However, pre-existing and ongoing co-morbid conditions such as poverty and violence continue to affect children and communities, and also influence the success of interventions targeted for HIV/AIDS care, treatment and prevention.

Mainstreaming an approach to the measurement of vulnerability and resilience of children affected by HIV/AIDS will allow us to track the impacts of children's contexts on key domains of their functioning, surviving and thriving. However, in mainstreaming vulnerability, we acknowledge that the contextual parameters affecting "OVC" are commonly the same as those affecting other children, including children orphaned or vulnerable due to other causes. How then do we take into account particularities of the HIV/AIDS context within this measurement approach?

The incorporation of the psychosocial indicators in the UNICEF guide underscores the importance of psychological functioning and social inclusion as critical measures of the response of governments to the welfare of children affected by HIV/AIDS. It also suggests that HIV/AIDS has brought new dimensions to the suffering for children and families in already difficult circumstances. Our understanding of the experience of children affected by AIDS is focused on the erosion of care and support networks as parents, extended family members and other caregivers become ill and die. Children may take on caretaking roles for sick parents and witness and experience the agony of the suffering and death of loved ones. There is a decline into worsening poverty with the loss of economic safety nets and adult wage earners, forcing many to withdraw from school and take up increased adult responsibilities for home care and work. Although families and communities remain the front-line of support for these children, increasing strains on social networks and community resources due to the pandemic leave many children abandoned and vulnerable to exploitation. The result may be separation of siblings among different households, children heading their own households and caring for younger siblings, or fending for their survival on the streets. There is a tragic loss of protected space for children to play, learn and grow with the safety and nurturance of adult guidance and care.

What then is unique in this experience of orphaning and being made vulnerable by HIV/AIDS as opposed to other causes, such as other chronic fatal illnesses, sudden death due to accidents or violence, and living in conditions of extreme poverty? And, further, what factors *mediate* the impacts of orphaning and vulnerability on outcomes for children's psychosocial health?

The scale of the pandemic and loss of previous gains in adult survival and other health and development indicators has particular consequences, especially for societies with high HIV prevalence. This is evident in the way it affects the network of people who support children in schools, health care centers and social services. In addition to the loss

of adults to support and protect children, much has been written on the loss of economic safety nets and deepening poverty for children affected by HIV/AIDS. These contextual issues, as well as others particular to the qualitative or “lived” experience of children affected by AIDS, point to potentially unique factors affecting well-being outcomes for children.

The following are areas for consideration in understanding what may be particular to the experience of children affected by HIV/AIDS:

1. The dynamics of poverty, HIV/AIDS and psychosocial health for children affected by HIV/AIDS.
2. The child’s experience of death, loss and grief due to HIV/AIDS: (i.e., prolonged illness, sequential losses of caregivers and changes in living situations, lack of support for children’s grieving processes due to shame and secrecy surrounding the disease).
3. Stigma and discrimination particular to societal values and beliefs around HIV/AIDS worsening the potential for abuse, exclusion and exploitation of children.
4. Increased risk of infection among HIV/AIDS-affected children (i.e., through survival risk behaviors or abuse) and heightened consequences of children’s risk behavior.

4.1 HIV/AIDS, Poverty and Psychosocial Health

It goes without saying that the vast majority of children affected by HIV/AIDS in sub-Saharan Africa are no strangers to the ravages of trans-generational, long term poverty. It is well established that enduring conditions of deprivation are likely to have profound effects on a wide range of child developmental outcomes.⁴¹ Furthermore, it is commonly accepted that HIV/AIDS disproportionately impacts poor communities⁴², and worsens the fragility of already poor families and their ability to provide a safety net for those who need care, such as children orphaned or made vulnerable.⁴³ Given the prolonged nature of the illness and its erosion of family resources, children are often left destitute.⁴⁴

According to Bray (2003), we can conclude that poverty is the principle vehicle through which AIDS works to further disadvantage children for a number of plausible reasons, including the likelihood of losing the other parent given the nature of disease transmission, and the tendency for the long course of illness to deplete household

⁴¹ McLoyd, V. (1998) Socio-economic disadvantage and child development. *American Psychologist*, 53: 185-204.

⁴² Geballe, S. and J. Gruendel. (1998) The Crisis Within a Crisis: The Growing Epidemic of AIDS Orphans. Lawrence Erlbaum Associates.

⁴³ Basaza, R. and Kaija, K. (2002) The impact of HIV/AIDS on children: Lights and shadows in the “successful case” of Uganda. In *AIDS, Public Policy and Child Well-being*, Cornia, G (ed.) Florence: UNICEF-IRC.

⁴⁴ Wild, L. (2003) The psychosocial adjustment of children orphaned by AIDS. Cape Town: University of Cape Town Department of Psychiatry, unpublished.

resources (as compared to deaths from other causes).⁴⁵ The increased risk of malnutrition, inadequate shelter, clothing and schooling are commonly cited as impacts of the death of wage-earning adults in AIDS-affected households.⁴⁶

However, studies on the disproportionate effects of poverty on children affected by HIV/AIDS compared to other children show mixed results. Stein (2003) notes that a review of comparative studies of orphans and non-orphans suggest orphans suffer more hunger than non-orphans⁴⁷; but a study by Cluver did not find that orphans were necessarily more disadvantaged than their peers in similar circumstances. As Wilson and Giese state: “While orphans, and in particular children orphaned by AIDS, do face some unique challenges, many of the areas of vulnerability that they face, such as hunger, being unable to pay school fees and poor access to health care services, are shared with children living in poverty.”⁴⁸ Thus, the social and economic dynamics of poverty, rather than AIDS-affectedness, appear to be the root causes of children’s vulnerability.⁴⁹ An important factor in these dynamics is stigmatization and its effects on increasing the vulnerability of children to abuse and exploitation. Economic abuse in particular (described further below) worsens conditions of poverty for OVC.

Poverty and HIV/AIDS also impact the education of affected children. Studies fairly consistently document that AIDS orphans have less access to education and lower enrollment rates than non-orphans.^{50 51} They may be unable to afford schools fees, uniforms or other supplies to attend school, or may have increased responsibility for care of younger siblings and household livelihood. Prior to the death of caregivers, children may assume the role of caretaker for sick adults and miss school because of worries about leaving their caregiver unattended. There is evidence that girls are more likely to be taken out of school than boys (likely due to their cultural role as caregivers).⁵² In addition, older children in AIDS-affected households may be at higher risk of non-attendance than their peers; although younger children also miss school, they may be

⁴⁵ Bray (2003)

⁴⁶ Muller, O., Sen, G. and Nsubuga, A. (1999) HIV/AIDS, Orphans and access to school education in a community in Kampala, Uganda. *AIDS Care* 13: 146-7.

⁴⁷ Makame, V., Ani, C., and Grantham-McGregor, S. (2002) Psychological well-being of orphans in Dar Es Salaam, Tanzania. *Acta Paediatrica*, 91: 459-65.

⁴⁸ Wilson, T., Giese, S., Meintjies, H., Croke, R. and Chamberlain, R. (2002) A conceptual framework for the identification, support and monitoring of children experiencing orphaning. *Children’s Institute, University of Cape Town* (commissioned by Save the Children).

⁴⁹ Stein, J. (2003) Sorrow makes children of us all: A literature review on the psycho-social impact of HIV/AIDS on children. *CSSR Working Paper No. 47*, University of Cape Town, Centre for Social Science Research.

⁵⁰ Desmond, C. and Gow, J. (2002) The current and future impact of the HIV/AIDS epidemic on South Africa’s children. In *AIDS, Public Policy and Child Well-being*, Cornia, G (ed.) Florence: UNICEF-IRC.

⁵¹ Foster and Williamson (2000)

⁵² Steinberg, M., Johnson, S., Schierhout, and Ndegwa, D. (2002) A survey of households impacted by HIV/AIDS in South Africa: What are the priority responses? Report submitted to Kaiser Family Foundation, Abt Associates, Inc.

taken out of school for shorter periods than older children who are more likely to have to work to support the household.⁵³

In addition to lowered access to education, Patel and Kleinman⁵⁴ describe a number of risk pathways for low educational levels among poor children: malnutrition may affect cognitive development and increase the risk for conduct disorders⁵⁵, both of which affect school performance and psychosocial development. If AIDs-affected children suffer higher rates of malnutrition, this risk pathway would disproportionately affect them. In addition, a review of studies cited by the authors in this paper show that low educational levels, as a poverty indicator, show the most consistent relationship with prevalence of common mental disorders and that the association between poverty and common mental disorders is universal regardless of a country's level of development. However, they also stress that "rather than actual income, factors such as insecurity, hopelessness, poor physical health, rapid social change and limited opportunities as a result of less education may mediate the risk of suffering from mental disorders."⁵⁶

These same mediating factors are commonly described for children affected by HIV/AIDS – stigma, humiliation, loneliness, relationship and livelihood insecurity, and the core experience of hopelessness – and need to be better understood in terms of their psychosocial outcomes. In addition, positive mediating factors also play an important role in determining children's intellectual, psychological and social development under conditions of stress. In a review of African and US-based studies, Wild concludes that children orphaned by HIV/AIDS will not invariably be dysfunctional, and that "family process variables and the supports available to children may be more important predictors of children's adjustment than the parent's illness or death *per se*."⁵⁷

4.2 The Experience of Death, Loss and Grieving for AIDS-Affected Children

As Stein states, we must acknowledge poverty as a primary psychosocial stressor for children affected by AIDS, in addition to the fact of orphanhood. Indeed, financial insecurity is certainly a paramount concern for OVC and children in poverty, and pressing material needs are often voiced by children affected by AIDS in qualitative studies. However, in the focus on material resources, there is a tendency to avoid the "hidden wounds" or emotional suffering of children affected by AIDS and coping with

⁵³ Booyesen, F. and Arntz, T. (2002) Children of the storm: HIV/AIDS and children in South Africa. *Social Dynamics*, 28 (1): 170-92.

⁵⁴ Patel, V. and Kleinman, A. (2003) Poverty and common mental disorders in developing countries. *Bulletin of the World Health Organization*, 81: 609-15.

⁵⁵ Lima, M., Beria, J., Tomasi, E., Conceicao, A., Mari, J. (1996) Stressful life events and minor psychiatric disorders: An estimate of the population attributable fraction in a Brazilian community-based study. *International Journal of Psychiatry and Medicine*, 26: 213-24.

⁵⁶ Patel and Kleinman (2003)

⁵⁷ Wild, L. (2001) The psychosocial adjustment of children orphaned by AIDS. *Southern African Journal of Child and Adolescent Mental Health*, 13 (1): 3-22.

grief and loss.⁵⁸ This quote by a 13 year old child taken from the National Children's Forum of HIV/AIDS 2001 illustrates the underlying emotional needs of OVC only rarely captured in typical assessments:

"My sister is 6 years old. I must look after her... There are no grown-ups living with us. I need a bathroom tap and clothes and shoes. And water also, inside the house. *But especially someone to tuck me and my sister in at night-time.*"⁵⁹ (emphasis, Stein 2003)

There is a paucity of literature on the grief reactions of AIDS orphans and few Africa-based studies. Certainly the death of a parent is a trauma for any child, but many factors complicate bereavement due to HIV/AIDS.⁶⁰ In addition to stigma, Stein outlines the following particular stressors in the experience of illness and death for OVC:⁶¹

1. Parenting with a terminal illness: There may be reversal of parent-child roles when the parent becomes ill, with the child assuming care for the household and sick parent often associated with an increased sense of social isolation.⁶²
2. Witnessing an HIV/AIDS death: Children often witness and nurse parents through the debilitating final stages of AIDS.
3. Psychological impact of death: Fear, a profound sense of insecurity and hopelessness may additionally complicate the grieving process for children.
4. Multiple losses: Children who lose a parent to AIDS are at risk for subsequently losing the other parent, younger siblings and other caregivers or loved ones.

In their examination of the impact of primary caregiver infection on child developmental outcomes, Swartz et al elaborate on the cumulative presence of a "set of material and psychosocial stressors" during the course of their caregiver/mother's illness as well as following the death. As household income decreases with illness of the primary breadwinner, children are more likely to experience disrupted schooling as they take on increasing caretaking roles and livelihood responsibility for the household.⁶³ These new roles increase their vulnerability to abuse and exploitation, and they are also at greater risk themselves for HIV infection.⁶⁴ However, Dawes et al also caution that the outcomes may not be all negative. Children may develop pro-social orientations and feel

⁵⁸ Daniel, M. (2003) Children without parents in Botswana: The safety net and beyond. Unpublished report.

⁵⁹ Stein (2003)

⁶⁰ Siegel, K. and Gorey, K. (1994) Childhood bereavement due to parental death from AIDS. *Developmental and Behavioral Pediatrics*, 15 (3): 66-70.

⁶¹ Stein (2003)

⁶² Smart, R. (2003) Children Living with HIV/AIDS in South Africa: A rapid appraisal. National HIV/AIDS Care and Support Task Team.

⁶³ Swartz, L., Brandt, R., Dawes, A., Bray, R., Mthembu-Salter, L. and Tomlinson, M. (2005) An exploratory study on the impact of primary caregiver HIV infection on caregiving and child development outcome in the era of HAART: Piloting the methodology. Report for the Organization for Social Science Research in Eastern and Southern Africa (OSSREA): HIV/AIDS Challenge for Africa Research Programme.

⁶⁴ Hunter, S. and Williamson, J. (2002) Children on the brink. Strategies to support children isolated by HIV/AIDS. Washington, DC: USAID.

proud of the support and assistance they give, while also feeling burdened by their situation.⁶⁵

In further examining the multiple losses experienced by children affected by HIV/AIDS, not only are OVC more likely to experience recurrent losses among their caregivers and family members,⁶⁶ they may also experience more frequent changes in households, schools and familiar surroundings as they are sent to live with extended families and again if those foster households are unwilling or unable to care for them. Evans notes that as the rights of AIDS-affected children are denied and they are rejected by extended family following death of their parents, different members of the household may engage in multiple migrations to cope with the impact of HIV/AIDS.⁶⁷ However, Bray notes that it is important to look at the history of child care arrangements in Africa, and fluidity of movement of family members to cope with various stressors (urban migration to alleviate poverty, strategies to cope with the rules imposed by apartheid in South Africa). Citing Jones (1993),⁶⁸ she notes that while one or both parents worked elsewhere, responsibilities for children's care shifted, often without any formal arrangements. Culturally, the care of biologically unrelated children is common practice in a number of African communities, although these have traditionally been temporary arrangements rather than formal and longer-term fostering.⁶⁹ Thus, it may be important to consider that the experience of loss in a mono-tropic attachment culture, may differ from that in which several caregivers play a role in the child's development.

Other research from South Africa has shown that migration in HIV/AIDS affected households is characterized by younger persons primarily to change caregivers in the immediate community; whereas migration in non-affected households tends to be of older persons for reasons of marriage, education or work.⁷⁰ Within this picture for OVC is the potential for separation of siblings,⁷¹ and the loss of a potentially important source of emotional and social support. One study found that over half of orphaned children in four districts in Zambia had been separated from their siblings, and 26% never saw their siblings.⁷² Another study in an urban area of Zambia found increased emotional disturbance in children separated from their siblings ($p=.05$).⁷³ In addition, children of

⁶⁵ Dawes, A, Bray, R., Kvalsvig, J., Rama, S. & Richter, L. (2004) Indicators of children's psychosocial development in the early childhood. Phase 1 & 2 Report for UNICEF. Cape Town: Human Sciences Research Council.

⁶⁶ Atwine et al (2005)

⁶⁷ Evans, R. (2005) Social networks, migration and care in Tanzania: Caregivers' and children's resilience to coping with HIV/AIDS. *Journal of Children and Poverty*, 11 (2): 111-29.

⁶⁸ Jones, S. (1993) Assaulting childhood: Children's experiences of migrancy and hostel life in South Africa. Johannesburg: Witwatersrand University Press.

⁶⁹ Bray (2003)

⁷⁰ Booyesen and Arntz (2002)

⁷¹ Ntozi, J. (1997) Effect of AIDS on children: The problem of orphans in Uganda. *Health Transition Review, Supplement to Vol. 7*, 23-40.

⁷² USAID/Zambia, DCOF, SCOPE-OVC/Zambia and FHI. (2002) Results of the Orphans and Vulnerable Children Head of Household Baseline Survey in Four Districts in Zambia.

⁷³ Nampaya-Serpell, N. (1998) Children orphaned by HIV/AIDS in Zambia: Risk factors from premature parental death and policy implications. Unpublished PhD, University of Maryland, Baltimore

AIDS-affected families may seek a “better life on the streets,” especially if maltreated in foster settings.

These recurrent losses of important caregivers and stable homes may lead also to recurrent and fluctuating experiences of grief and mourning.^{74 75} In a study of AIDS orphans in rural Uganda, the loss of parents seemed to be still fresh in the minds of the children (67.5% reported they still cried when thinking of their parents) even though many had lost their parents years ago.⁷⁶ A study of youth heading households in Rwanda showed similar findings: 50-60% of OVC aged 15-18, the majority of whom had been heading households for more than four years, reported still feeling bothered by their parents’ death.⁷⁷ Although these findings are perhaps not surprising, they may point to experience of complicated bereavement for children who may have experienced multiple traumas and hardships in the course of the parent’s illness and death. Moreover, with the experience of multiple losses of loved ones, children themselves may worry about becoming ill and dying.

Although younger children may not have the capacity to fully understand and recover from the grieving process,⁷⁸ adults may also keep knowledge of deaths from children for cultural reasons. In the same study in Zambia, one-third of OVC caregivers refused to answer questions on whether or not the child in their care knew the cause of death of their parents, or ever talked about their parents’ death. The authors state these findings are not surprising given cultural taboos around discussions of death in general or impending death, especially with children. Although 33% stated they themselves talked with the child about their parents’ death, 36% believed the orphan did not know the reason their parent died.⁷⁹

Research in traditional South African Nguni language communities shows that caregivers believe children only feel the loss of a parent around age 12 -14 years. They explain that children age 5-6 years miss a parent who is absent, but don’t realize the parent has actually died. Adults from these communities admit to feeling uncomfortable discussing death with children and therefore avoiding the conversations. They may let children assume the parent is away working in another place or allow children to eventually learn of the death through neighborhood gossip.⁸⁰ Similar accounts have come from research in Botswana:

"In response to the question on how death is explained to children in the Setswana culture, the participants concluded that they do not adequately explain death to children: sometimes an adult will whisper in a sleeping child’s ear, sometimes a child is told his mother has gone on a journey

⁷⁴ Foster, G. (2002) Beyond education and food: psychosocial well-being of orphans in Africa. *Acta Paediatrica*, 91: 502-4.

⁷⁵ Makame et al (2002)

⁷⁶ Atwine (2005)

⁷⁷ Boris, N., Thurman, T., Snider, L., Spencer, E. and Brown, L. (in review) Infants and children living in youth-headed households in Rwanda: Implications of emerging data. *Infant Mental Health Journal*.

⁷⁸ Carr, A. (1999) *The handbook of child and adolescent clinical psychology*. London: Routledge.

⁷⁹ USAID/Zambia (2002)

⁸⁰ Daniel, M. (2005) Beyond liminality. Orphanhood and marginalisation in Botswana. *African Journal of AIDS Research*, 4(3): 195-204.

or her father has gone to the mines. Other phrases are slightly more realistic in that they give an indication that death is permanent, for example, *o jelwe ke ditau* (she has been eaten by lions).⁸¹

In addition to an unwillingness to engage children in conversations about death, children are often kept away from funerals. Children in Masiphumelele (urban poor community near Cape Town, SA) only attend the funerals of close family members and otherwise are left in the care of a neighbor.⁸² Likewise in the Botswana study, children are frequently excluded from the funeral, and are not allowed to talk about the deceased or view the corpse.⁸³ These practices potentially limit the opportunity for children to grieve, understand and resolve the death of loved ones.

However, it appears that with rising death rates in many communities, ‘old ways’ are changing in regards to attitudes and practices around burials and children’s grieving.⁸⁴ As people adapt to the scale of deaths in communities, less time may be devoted to mourning each deceased person.⁸⁵ However, Semomung (2003) notes that adults in the Botswana study agree that the traditional methods for explaining death to children are insufficient and irrelevant, and may even erect barriers of secrecy and fear which undermine the child’s trust in adults: “Children’s feelings are never acknowledged, therefore they make their own analysis and some may end up blaming themselves and feeling guilty; they will end up failing to cope.” They agreed the best response was telling children the truth, taking the child’s age into consideration.⁸⁶

4.3 Stigma and Discrimination of HIV/AIDS-Affected Children

Stigma is likely the most particular stressor for OVC, being the root cause of neglect, social isolation and vulnerability to abuse following the death of a parent to HIV/AIDS.⁸⁷ An example is the economic abuse of OVC. Welfare grants for orphans may be diverted by foster caregivers for other uses, children may be used for cheap labor and some orphans may be dispossessed of their assets by relatives or neighbors.^{88 89} The director of a home-based care programme in Mpumalanga (cited in Stein, 2003) stated: “If we do not get to the children within eight hours of them being orphaned, they lose their possessions and homes to neighbors who come in and evict the children.”⁹⁰ Children may also be exploited for cheap labor or underpaid for their services. A survey of 692 youth aged 13-

⁸¹ Ibid.

⁸² Dawes, A. (2006), personal communication.

⁸³ Daniel (2005)

⁸⁴ Dawes, A., Bray, R. Kvalsvig, J., Kafaar, Z., Rama, S. & Richter, L. (2004) Indicators of South African children’s psychosocial development in the early childhood period. Phase 3 Report for Unicef South Africa. Cape Town Human Sciences Research Council (available at www.hsrc.ac.za).

⁸⁵ Makame (2002).

⁸⁶ Cited in Daniel (2005).

⁸⁷ Stein (2003)

⁸⁸ Foster, G. a (1997) Children rearing children: A study of child-headed households. Paper presented at *The Socio-demographic Impact of AIDS in Africa Conference*, University of Natal.

⁸⁹ Webb, D. (1995) Who will take care of the AIDS orphans? *AIDS Analysis Africa* 5(2): 12-13.

⁹⁰ Loening-Voysey, H. (2002) HIV/AIDS in South Africa: Caring for vulnerable children. *AJAR* 1: 103-10.

24 heading households in Rwanda illustrates these problems: 26% reported being hired for work and not paid, 36% reported persons have tried to steal their land or property, and 51% reported someone has tried to damage or destroy their land, crops or animals.⁹¹

Stigma may also affect whether or not children and families affected by HIV/AIDS have access to and utilize welfare grants and other services. They may be discriminated against and excluded from basic social services and education by service personnel.⁹² They may also choose to avoid using services or grants in order to hide their vulnerability⁹³ or the fact of their HIV-affectedness.

Stigma is another factor which influences whether or not, and how, children are told about a parent's death due to HIV/AIDS, as well as caregivers' disclosure of their HIV status to children. In her study of orphans in South Africa, Cluver notes that because of stigma and the fact that few children are aware of the cause of their mother's death, she was unable to mention "HIV/AIDS" on any information sheets or survey instruments.⁹⁴ Given the potential for discrimination and abuse of children from AIDS-affected families, it is not surprising that caregivers would withhold their HIV-status or HIV as a cause of death from children out of a desire to protect them from further harm.⁹⁵

Critical to children's surviving and thriving in difficult circumstances is their ability to access functional networks of support and a sense of inclusion to larger cultural and societal supports that provide a buffer to threat exposure. Social exclusion and marginalization of OVC, both prior to and after the death of caregivers, is a consequence of stigma and a barrier to their full participation in society. It is also an important mediating factor in their protection from abuse and is likely to have a range of consequences for psychosocial well-being outcomes.

In some studies, the source of stigma and discrimination may come from the extended family. Although the principle support for orphans in Africa remains the extended family, some relatives exploit or abuse children, or fail to meet their health and schooling needs.⁹⁶ Extended family are all too often the culprits of exploitation and property grabbing following death of parents.^{97 98} Child-headed households in Rwanda, Uganda

⁹¹ Snider (2005)

⁹² Nelson Mandela Children's Foundation (2001) Situation analysis of child-headed households in South Africa. NMCF.

⁹³ Daniels, M. (2003) Children without parents in Botswana: The safety net ad beyond. Paper presented at *A Scientific Meeting on Empirical Evidence for the Demographic and Socio-Economic Impact of AIDS*, HEARD, University of Natal, Durban, SA.

⁹⁴ Cluver, L. and Gardner, F. (in press) The psychological well-being of AIDS orphans in Cape Town, South Africa. *Annals of General Psychiatry*.

⁹⁵ Siegel and Gory (1994)

⁹⁶ Foster, G., Shakespear, R., Chinemana, F., Jackson, H., Gregson, S. and Mashumba, S. (1995) Orphan prevalence and extended family care in a peri-urban community in Zimbabwe. *AIDS Care*, 7 (1): 3-17.

⁹⁷ Ntozi, J.P., & Mukiza-Gapere, J. (1995) Care for AIDS orphans in Uganda: findings from focus group discussions. *Health Transition Review*, 5(Suppl.): 245-52.

⁹⁸ Foster, G., Makufa, C., Drew, R., Mashumba, S., and Kambeu, S. (1997) Perceptions of children and community members concerning the circumstances of orphans in rural Zimbabwe. *AIDS Care*, 9(4): 391-405.

and Zimbabwe have reported neglect from their relatives,^{99 100} and many indicate that their relatives never come to visit them.¹⁰¹ In Rwanda, Human Rights Watch found that OVC consider family members to be more exploitive than strangers, and in another study orphaned children listed relatives as their least important source of support. These findings were corroborated by another study of youth-headed households which found that although the majority of orphans had contact with relatives (40% had daily contact), they found these relationships to be unsupportive and even abusive. Fifty-two percent reported that relatives take advantage of them, and 63% stated they did not trust relatives to look out for their best interests.

In the same study of youth-headed households in Rwanda, half reported feeling that no one cared for them and that they were isolated from the community. In fact, 57% reported the community would rather hurt them than help them, over half reported enacted stigma, and 86% felt rejected by their community. (However, the authors also emphasize that historical factors related to social mistrust due to the genocide also be taken into consideration in these findings.)¹⁰²

The increasing emergence of child and youth-headed households has been viewed by some as evidence of decreasing social support for children in AIDS-affected areas. This is because one measure of community support in areas with large numbers of OVC has been the absorption of orphans into extended family systems. However, other evidence suggests that child-headed households may have supportive relationships with siblings, peers and unrelated community adults¹⁰³ and many report close ties with relatives.¹⁰⁴ Although reasons for the existence of child-headed households can relate to the reluctance of extended family or other adults to care for them, children may choose to live together even without adult support in order to stay together, keep their land and property or to fulfill a dying parent's wish for the family to stay intact.¹⁰⁵

In reference to behavioral outcomes for children affected by HIV/AIDS, Bray notes that children lacking a nurturing caregiver are not prone to externalizing or anti-social behavior, “*unless* they live in communities that exclude, abuse, condemn and abandon them.”¹⁰⁶ She is referring here to a fear that has been expressed that children growing up in such difficult circumstances without proper adult care may develop psychosocial disorders and severe behavior problems that carry on to adulthood, destabilizing the

⁹⁹ World Vision Rwanda, & UNICEF Rwanda (1998). Qualitative needs assessment of child headed households in Rwanda.

¹⁰⁰ Walker, L. (2002). ‘We will bury ourselves’. A study of child-headed households on commercial farms in Zimbabwe. Harare, Zimbabwe: Farm Orphan Support Trust of Zimbabwe.

¹⁰¹ Ayieko, M. (1997). From single parents to child-headed households: The case of children orphaned by AIDS in Kisumu and Siaya districts. Study Paper No 7. UNDP, HIV and Development Programme.

¹⁰² Thurman et al (2006)

¹⁰³ Ledward and Mann (2000)

¹⁰⁴ Foster and Williamson (2000)

¹⁰⁵ Ibid.

¹⁰⁶ Bray (2003)

future security of societies.^{107 108 109} No doubt this will be true of some young people. However, the fantasy of un-socialized hordes of youth being spawned by the AIDS pandemic has come under strong criticism for ignoring the positive coping strategies that are adopted by significant numbers of children and youth in difficult circumstances.¹¹⁰ It is itself a reflection of the stigmatization of children affected by HIV/AIDS. These concerns for ‘lost generations’ of so-called ‘AIDS orphans,’ and fears of a rising tide of unsocialized youth echo the rhetoric of 1980’s South Africa when black youth involved in the liberation struggle were at once portrayed as both victims and villains – the pejorative construction of another lost generation in another time – but based on similar adult fears.¹¹¹ It also ignores the fact that the pandemic is likely to engender a range of pro-social behaviors as children and adolescents take responsibility for those in their homes who are sick, or who assist in many diverse ways to provide for the family. Finally, the emphasis on massive social disruption tends to push aside the real feelings and experiences of children – the consequences of grief and trauma that matter most to them.¹¹²

4.4 Increased Risk of Infection in HIV/AIDS-Affected Children

In high prevalence areas, 50% of new HIV cases are found in young people aged 15-24 years, with girls affected at younger ages.¹¹³ Studies have shown that AIDS orphans tend to begin sexual activity earlier than their non-orphaned peers, and are especially vulnerable to coercive sex and report increased sexual abuse.¹¹⁴ One study in Rwanda found that 9% of girls heading households reported sexual abuse,¹¹⁵ and qualitative research with secondary school girls in rural Zimbabwe revealed that sexual abuse was felt to be the greatest problem facing young women affected by HIV/AIDS (including propositioning by teachers, peers, and others in the community).¹¹⁶ A recent study in Zimbabwe found that single orphans were more likely than non-OVC to have started sex. Further, being out of school and increased psychosocial disorder were associated with early onset of sexual activity ($p < .005$), and more pronounced psychosocial disorder

¹⁰⁷ Hunter, S. (1990) Orphans as a window on the AIDS epidemic in sub-Saharan Africa: Initial results and implications of a study in Uganda. *Social Science and Medicine*: 31: 681-90.

¹⁰⁸ Dorrington R., Bourne, D., Laubscher, R. and Timaeus, I. (2001) The impact of HIV/AIDS on adult mortality in South Africa. (*Tech. Rep.*) Cape Town, South Africa: Medical Research Council, Burden of Disease Research Unit.

¹⁰⁹ Karlenza, X. (1998) Confronting the social consequences of AIDS. *Child and Youth Care*, 16: 4-6.

¹¹⁰ Bray (2003)

¹¹¹ Straker, G. (1989) From victim to villain: a ‘slight’ of speech? Media representations of township youth. *South African Journal of Psychology*, 19: 20-27.

¹¹² Stein, J (2003)

¹¹³ Atwine B., Cantor-Graae, E., Bajunirwe, F. (2005) Psychological distress among AIDS orphans in rural Uganda. *Social Science and Medicine*, 61: 555-64

¹¹⁴ UNAIDS Joint United National Programme on HIV/AIDS (2002). *AIDS Epidemic Update*, Dec 2002.

¹¹⁵ Snider, L. (2005) Care and protection of child-headed households in Rwanda: Findings from focus groups and a baseline survey. Presented at Emory University Institute for Human Rights Conference, *Lessons Learned from Rights Based Approaches to Health*, Atlanta, GA.

¹¹⁶ Gilborn, L., Apicella, L., Brakarsh, J., Dube, L., Jemison, K., Kluckow, M., Smith, T. and Snider, L. (2006) Orphans and vulnerable youth in Bulawayo, Zimbabwe: An exploratory study of psychosocial well-being and psychosocial support programs. *Horizons Final Report*, Washington, D.C.: Population Council.

showed an independent association with early onset of sexual activity. In this study, reports of forced sex were uncommon, but paternal orphans were especially at risk – they were five times more likely than non-orphans to report forced sex.¹¹⁷

In addition, AIDS orphans are more vulnerable to transactional sex, many of whom exchange sex for material goods to relieve poverty or for protection.¹¹⁸ Sexual abuse and sexual risk behaviors are a serious consequence of the socio-economic dynamics of poverty, stigma and HIV/AIDS, and also must be considered in light of the increased risk of HIV infection in OVC, increased spread of the epidemic in the near future, and renewal of the social and economic cycle of HIV/AIDS in poor families.¹¹⁹

¹¹⁷ Nyamukapa, C., Gregson, S., Lopman, B., Saito, S., Watts, H., Monasch, R. and Jukes, M. (2006) HIV-associated orphanhood and children's psychosocial disorders: Theoretical framework tested with data from Zimbabwe. Biomedical Research and Training Institute Harare, Imperial College London and UNICEF Zimbabwe.

¹¹⁸ Gilborn, L. (2002) In the public eye – beyond our borders, the effects of HIV infection on children in Africa. *Western Journal of Medicine*, 176: 12-14.

¹¹⁹ Bray (2003)

5. Africa-Based Literature and Instrument Review: Discussion of Findings

There remains a paucity of literature on the psychosocial well-being of orphans and vulnerable children in developing country contexts. This compilation draws upon studies conducted in sub-Saharan Africa, including both quantitative and qualitative studies of adolescents orphaned and made vulnerable by HIV/AIDS, as well as related studies of adolescents exposed to violence or war. Adaptations of standardized survey instruments, and their psychometric properties where available, are provided. Newly developed measures for psychosocial vulnerability and resilience found in the grey literature are also included.

The review is limited to adolescents consistent with the age range of respondents for the UNICEF psychosocial indicators, and because of the unique developmental aspects of this age group in terms of emotional, social, behavioral competencies and particular risks of importance to the development of relevant measures. For example, older adolescents have a better ability to express their feelings than younger children, undergo physical changes with the onset of puberty, develop new social capacities in peer and other relationships as well as abstract cognitive abilities, and face particular challenges with the onset of sexual activity and risk of HIV infection.¹²⁰

5.1 Methodologic Limitations in Africa-Based Research

Building on an initial review of instruments utilized in US-based research by Balaban (2005),¹²¹ this compilation also utilizes a review by Lucie Cluver and colleagues¹²² and a review compiled by Thurman & Snider and colleagues for the Bernard van Leer Foundation,¹²³ among other sources.

Balaban's review drew upon the Thurman & Snider review and personal communication with Cluver. The Thurman & Snider review identified 18 studies worldwide (16 published): 8 focused on the psychological impacts of parental HIV/AIDS on children, 5 (all in Africa) focused on social support to orphans and 3 (all US-based) focused on impact of interventions for psychosocial well-being of children affected by HIV/AIDS. A total of nine of the eighteen studies were Africa-based. Of the 9 Africa-based studies, two used adapted, standardized assessment instruments and control groups: Makame et al (2002) studied 41 orphans and 41 non-orphans in Tanzania; and Sengendo & Nambi (1997) studied 169 orphans matched with 24 non-orphans in Uganda. Wolff & Gebremeskel (1999) also utilized adapted, standardized surveys in a longitudinal study of

¹²⁰ Atwine et al. (2005)

¹²¹ Balaban, V. (2005) Methods for assessing psychosocial wellbeing of children and adolescents. Draft compiled for UNICEF Expert Consultation: *Measurement of Psychosocial Wellbeing among Orphaned and Vulnerable Children*, NY, July 2005.

¹²² Cluver, L. and Gardner, F. (2006) *The Psychological Well-being of Children Orphaned by AIDS: A Review of International Quantitative Evidence*.

¹²³ Thurman, T., Littrell, M., Tuneberg, S. and Snider, L. (2005) *Compilation of resources: Measurement approaches for children affected by conflict and HIV/AIDS*. For Bernard van Leer Foundation *Road to Toronto Workshop Series*, March 2005.

72 orphans aged 4-7 in Eritrea, but had to use two separate comparison groups for the initial baseline measures (non-orphaned refugees) and the five-year follow-up (unaccompanied children who spent the war in institutions but unexposed to combat for the follow-up study). The other six Africa-based studies were descriptive and did not use standardized instruments. Methodologies varied considerably between the studies in this review, and given that few used control groups, it is difficult to make meaningful comparisons of results.

Cluver’s (2006) review is more comprehensive and reflects emerging new research. However, overall she notes that studies of the mental health of children orphaned by HIV/AIDS are “limited, scattered and often unpublished.”¹²⁴ Her review focused on quantitative research exploring psychological outcomes for uninfected, parentally bereaved children due to HIV/AIDS. Of twenty total studies, she found 15 based in Africa (2 are ongoing) and nine of which used control groups - these include Makame (2002) and Sengendo & Nambi (1997) cited above. [see table below] However, she also noted a wide variation in sample characteristics (often small sample sizes), outcome measurements and control groups (limited or no control groups). All of the Africa-based studies she reviewed are cross-sectional. One study (Poulter, 1996) interviewed caregivers only, one interviewed both children and caregivers (Manuel, 2002), and the rest interviewed only children with no triangulation of data from caregiver reports. Cluver reports that of all studies she reviewed (including also five US-based studies), 13 (of 17 studies which measured them) found internalizing problems and 5 (of 11 studies which measured them) found externalizing behaviors among orphans.

Africa-Based Studies Utilizing Control Groups in Cluver & Gardner’s Review (2006)

Authors	Country	Population Studied	Respondent/Instrument
Poulter et al (1996)	Zambia	22 hh with orphans 66 hh with HIV+ parents 75 control families	Rutter scales, Caregiver reports only
Makame et al (2002)	Tanzania	41 orphans 41 non-orphans	Adapted Rand and Beck Inventories with children
Sengendo & Nambi (1997)	Uganda	169 orphans 24 non-orphans	Non-standardized depression scale with children
Manuel et al (2002)	Mozambique	76 orphans 74 non-orphans caregivers	Non-standardized questionnaire based on Makame et al (2002) Children and caregiver reports
Cluver & Gardner (in press)	South Africa	30 orphans 31 non-orphans	Adapted SDQ and IES
Atwine et al (2005)	Uganda	123 orphans 110 non-orphans	Beck Youth Inventories of Emotional and Social Impairment
Bhargava (2005)	Ethiopia	1000 maternally orphaned children by AIDS or other causes	60 of 657 items from MMPI
Wild et al (in press)	South Africa	81 AIDS orphans 78 ‘other causes’ orphans 43 non-orphans	R-CMAS, CDI, items from the CBCL-YSR and the SEQ; and examination of moderating factors
Cluver & Gardner (in press)	South Africa	451 AIDS orphans 243 ‘other causes’ orphans	CDI, R-CMAS, CBCL, Children’s PTSD Checklist

¹²⁴ Cluver & Gardner (2006)

analysis)		85 'unknown cause' orphans 277 non-orphans	
-----------	--	---	--

Cluver emphasizes the need for “further, rigorous research into mental health, and risk and protective factors for children orphaned by AIDS.”¹²⁵ In 1993, Wild (cited in Stein, 2003)¹²⁶ observed that “at present, knowledge about the psychosocial adjustment of AIDS orphans is based on an intermingling of sound data, less reliable data and clinical observation, and is therefore somewhat less secure than might appear at first glance.” There has been an increasing focus on data from sub-Saharan Africa over the last several years. Compared with the 20 studies she found in her 2006 review, Cluver cites Wild’s review of 2001 which found only 8 studies of psychological outcomes for orphaned children (6 published, 2 unpublished), of which only 2 were Africa-based and only 1 utilized a non-orphaned control.¹²⁷

Researchers in the field appear to be improving the rigor of methods in more recent studies (some as yet unpublished) with increasing use of matched control or comparison groups, longitudinal assessments, use of standardized instruments and in-depth qualitative work for validation and adaptation of instruments into local languages and concepts. However, Bray¹²⁸ (cited in Cluver, 2006) cautions that “the most striking features of the literature existing on the impact of HIV/AIDS on children, are the scarcity of reliable data, and the alarming reliance of a few, localized studies, in supporting arguments on a more general level.” We therefore recommend that emerging data be monitored and added to this review, including forthcoming findings from Cluver & Gardner’s ongoing controlled study in South Africa, and a longitudinal study of youth-headed households in Rwanda (interim findings published by Brown et al, 2005¹²⁹).

5.2 Challenges in Assessing Psychosocial Wellbeing in Developing Country Settings

Various challenges exist in assessing the emotional wellbeing of adolescents in developing countries. Researchers have used both quantitative and qualitative methods to better understand wellbeing and distress in terms of behavior, functioning, cognition and emotions. Stein notes that “it is difficult to compare findings across the available research, given the variety of methods used – from ethnographic interviews to quantitative psychological assessment measures.”¹³⁰ In addition, the interpretation of existing data – especially that derived from standardized scales originally developed in

¹²⁵ Ibid.

¹²⁶ Stein (2003)

¹²⁷ Wild, L. (2001) The psychosocial adjustment of children orphaned by AIDS. *Southern African Journal of Child and Adolescent Mental Health*, 13 (1).

¹²⁸ Bray, R. (2004) AIDS orphans and the future: a second look at our predictions. Medical Research Council of South Africa, *AIDS Bulletin* 13 (2).

¹²⁹ Brown, L., Thurman, T. and Snider, L. (2005) Strengthening the psychosocial wellbeing of youth-headed households in Rwanda: Baseline findings from an intervention trial. *Horizons Research Update*. Population Council, USA.

¹³⁰ Stein (2003)

Western contexts – is especially difficult due to socio-cultural and linguistic differences. Stein notes that many of the standardized scales used in psychological assessments in Africa have not been assessed for their appropriateness and “the fact that research is conducted in an African setting does not mean that it is not designed using Western psychological norms.”¹³¹

As Snider et al state, “The expression, recognition and treatment of mental disorders are rooted in culture and social context. Psychiatric diagnostic schemes and treatment approaches reflect an individualist context that may be inappropriate for collectivist societies.” For example, the development of “self-concept” (related to measures of self-esteem and locus of control in several studies) is tied to social interdependence in collectivist societies – very different from the individualist societies of the Western world.¹³² Further, inappropriate approaches to psychosocial assessment have the potential to cause harm – through exposing the respondent to distress through the recounting of sensitive or traumatic material usually not revealed to strangers, or probing on mental health issues that may be severely stigmatized in the culture.¹³³

There is also a danger in assuming that findings from studies in one African setting are relevant in all African contexts.¹³⁴ *Africa* is composed of diverse cultural, economic, social and political contexts with large variations between countries and in urban and rural areas within countries. As Dawes & Honwana explain, “When speaking of culture in Africa, we cannot stress enough, that the continent possesses a range of cultural ways of being. Africa is **not** just the culture of so-called ‘traditional’ rural people. Contemporary African studies have a hybrid cultural character, displaying the influence of both the East and the West. While containing a substantial modern sector, they are predominately pre-industrial. These features commonly live together in the same communities, and even in the same individuals.”¹³⁵

Various examples from existing research call into question the relevance of standardized scales and constructs for African settings. One of the dangers of indiscriminate application of Western schema around emotional health and functioning as described by Kleinman is “category fallacy” – the false idea that symptoms described in different context share the same meaning. In addition, many researchers have found that descriptors for local syndromes utilize terms and concepts foreign to a Western understanding of emotional disorder, such as various bodily sensations or even dissociative experiences.¹³⁶ Patel et al note that there are no direct equivalents in the

¹³¹ Ibid.

¹³² Eaton, L., and Louw, J. (2000) Culture and Self in South Africa: Individualism-Collectivism Predictions. *J. Soc Psychology*, 140(2): 210-217.

¹³³ Snider, L., Cabrejos, C., Huayllasco, E., Trujillo, J., Avery, A. and Aguilar, H. (2004) Psychosocial assessment for victims of violence in Peru: The importance of local participation. *Journal of Biosocial Science*, 36: 389-400.

¹³⁴ Stein (2003)

¹³⁵ Dawes, A. and Honwana, A. (1998) Children, culture and mental health: Interventions in conditions of war. In *Rebuilding Hope: Congress on Children, War and Persecution*, Maputo, Mozambique, 74-81.

¹³⁶ Kleinman, A. (1987) Anthropology and psychiatry: the role of culture in cross-cultural research on illness. *British Journal of Psychiatry*, 151: 447-454.

Zimbabwean Shona language for “depression” and “anxiety,” and most depressed individuals attribute their symptoms to “thinking too much” (*kufungisisa*), to a supernatural cause and to social stressors. The word “depression” connotes an illness which rarely presents with emotional symptoms.¹³⁷

Local syndromes do not always correlate to Western diagnostic categories. One syndrome described by Rwandese is *guhahamuka*, which appears to blend key symptoms of depression and PTSD, separate but highly co-morbid conditions in Western societies.¹³⁸ Bolton describes a “depression-like” syndrome in Rwanda – *agahinda gakabije* – which, although similar to depression, is a more general disorder including both short-term grief and chronic symptoms. Although most respondents diagnosed in his study with depression also had *agahinda*, many *agahinda* sufferers did not have corresponding depression. He also notes that the expression of depression may vary not only among different populations, but also different genders.¹³⁹

Linguistic challenges were evident in a study by Wild et al, who found that the internal consistency of the Self-Esteem Questionnaire used with adolescents in Cape Town diminished as it was translated from English into Afrikaans and further as it was translated for use with Xhosa-speaking youth. Xhosa-speaking youth had particular difficulties with subscales related to sports/athletics, body image and global self-esteem. The authors speculate that “certain English concepts and phrases cannot be meaningfully translated into Xhosa, a Bantu language that has a very different grammatical structure from the West Germanic languages of English and Afrikaans.”¹⁴⁰

An additional challenge for the creation of measures for the national-level indicators is in capturing emotional distress and wellbeing in age-appropriate terms for adolescents. Makame & McGregor note in adapting the Rand and Beck depression inventories for their study of children in Tanzania that after piloting, “considerable modifications of the wording were made, not only to translate into Swahili but also to put into the vernacular of the children.”¹⁴¹ In their study in Rwanda, Boris et al found that there is no term for “stress” in Kinyarwanda, and items under this construct were reclassified as measures of depression or anxiety. However, they also report that their formative qualitative research showed that western tools such as the CES-D (Center for Epidemiologic Studies – Depression) had face validity with Rwandan youth and could be adequately translated into Kinyarwanda.¹⁴²

¹³⁷ Patel, V., Abas, M., Broadhead, J., Todd, C. and Reeler, A. (2001) Depression in developing countries: Lessons from Zimbabwe. *British Journal of Medicine*, 322: 482-4.

¹³⁸ Bolton, P. (2001) Local perceptions of the mental health effects of the Rwandan genocide. *J Nerv Ment Dis*, 189 (4): 243-8.

¹³⁹ Bolton, P. (2001) Cross-cultural validity and reliability testing of a standard psychiatric assessment instrument without a gold standard. *Journal of Nervous and Mental Disease*, 189 (4): 238-42.

¹⁴⁰ Wild, L.G., Flisher, A.J., Bhana, A. & Lombard, C. (2005) Psychometric properties of the self-esteem questionnaire for South African adolescents. *South African Journal of Psychology*, 35: 195-208.

¹⁴¹ Makame, V., Ani, C., Grantham-McGregor, S. (2002) Psychological wellbeing of orphans in Dar Es Salaam, Tanzania. *Acta Paediatr* 91 (4): 459-65.

¹⁴² Boris, N., Thurman, T., Snider, L., Spencer, E., and Brown, L. (in press) Infants and Young Children Living in Youth-Headed Households in Rwanda: Implications of Emerging Data. *Infant Mental Health Journal: Culture and Infancy Special Issue*.

Likewise, in examining the validity of Western medical models of depression for Zimbabwe, Patel et al explain that although multiple somatic complaints – especially those of the heart and head which are cultural metaphors for fear or grief – are the most common presentation of depression, most patients will admit to cognitive and emotional symptoms when asked. They also found a high degree of agreement (80%) between the Who Self-Reporting Questionnaire and the Shona Symptom Questionnaire (written in the local language) when applied to patients in primary care facilities.¹⁴³

Where one does not know the health status of the individual being interviewed and where HIV and AIDS are highly prevalent, there is a real risk that instruments measuring depression (and which include somatic items) will produce false positive results because the symptoms of the physical illness and the emotional state overlap.^{144 145 146} Recent analysis of data gathered for an ongoing study of the psychological status of isiXhosa speaking women living with AIDS in a poor Cape Town community shows that those who rate their physical wellbeing as poor have elevated scores on the CES-D. When the somatic items are removed, the effect disappears.¹⁴⁷

Furthermore, it has been established that syndromes such as depression, anxiety and post-traumatic stress disorder do exist across many cultures and cause significant morbidity and disability worldwide.^{148 149} However, capturing the experience of emotional distress across languages and cultures has proven challenging in field research. Personal communication with colleagues and several of the authors in this literature review underscored the difficulties in adapting standardized instruments to local understandings. Brandt, for example, noted confusion by HIV-negative respondents to question about emotional distress that were more easily answered by HIV-positive respondents in her ongoing study of women caregivers in South Africa.¹⁵⁰ As the HIV-positive respondents in her study were receiving counseling, a possible explanation is the emotional fluency gained by recipients of psychosocial interventions giving them language (albeit a more Western language) for expressing emotional distress which may have previously been unexpressed or expressed in different terms. Gilborn et al in their study of the psychosocial impacts of interventions for youth in Zimbabwe suggested a similar

¹⁴³ Patel et al (2001)

¹⁴⁴ Kalichman, S. (1995) *Understanding AIDS: A guide for mental health professionals*. Washington, D.C.: American Psychological Association

¹⁴⁵ Kalichman, S., Rompa, D. and Cage, M. (2000) Distinguishing between overlapping somatic symptoms of depression and HIV disease in people living with HIV/AIDS. *Journal of Nervous and Mental Disease*, 188: 662-70.

¹⁴⁶ Schulberg, H., Saul, M., McClelland, M., Ganguli, M., Christy, W. and Frank, R. (1985) Assessing depression in primary medical and psychiatric practices. *Archives of General Psychiatry*, 42: 1164-70.

¹⁴⁷ Rene Brandt, personal communication, August 2006.

¹⁴⁸ Mollica, R., Caspi-Yavin, Y., Bollini, P., Truong, T., Tor, S. Lavelle, J. (1992) The Harvard Trauma Questionnaire: validating a cross-cultural instrument for measuring torture, trauma, and posttraumatic stress disorder in Indochinese refugees. *J Nerv Ment Dis*, 180: 111–116.

¹⁴⁹ Patel and Kleinman (2003)

¹⁵⁰ Brandt, R., personal communication (2006)

explanation in their finding that youth with greater exposure to psychosocial interventions reported increased levels of emotional distress.¹⁵¹

Bolton recommends an approach to achieving not only criterion validity, but also conceptual validity in questionnaires by using local descriptions of syndromes in people's native language, and a qualitative analytic process in that language, to create a quantitative instrument measuring emotional distress in local terms. A quantitative study and factor analysis is then used to determine if the instrument accurately reflects the local syndromes, and lastly if these are similar to our conceptions of mental illness in the West. This avoids the common pitfall of the traditional approach to translating and back-translating standardized English questionnaires into local languages because as Bolton states "if the questions are truly not directly translatable, you'll never get a good question."¹⁵² These methods may be more time intensive, given the depth of qualitative and/or ethnographic formative research required. But given the pay-offs in improved validity of the measures, more researchers are utilizing in-depth qualitative assessments to develop locally grounded survey instruments or to complement adaptations to standardized survey instruments for emotional distress.^{153 154 155} Thurman et al note that "the considerable effort [expended] in piloting our survey and assuring its face validity... was likely key in establishing the scale's favorable psychometric properties." That process included focus groups, free listing, piloting as well as a thorough review by a local technical committee of all survey items with revisions based on language, culture and socio-political context.¹⁵⁶

Bolton recommends this method especially in the absence of a "gold standard" for criterion validity, which in cross-cultural mental health assessments generally utilizes "an assessment by a psychiatrist or psychologist, or comparison with another instrument known to have high validity among the local population."¹⁵⁷ However, these are rarely available in developing country settings. Atwine et al note that they were unable to conduct an external validation of their adaptation of the Beck Youth Inventory for Ugandan youth, as no other sources of information about these children were available.¹⁵⁸ Similarly, Poulter states, "There has been no large-scale survey of children in Zambia using psychological measurement tools, or indeed any other methods, which would give a baseline assessment to determine what is 'normal' psychological functioning in Zambian children... Child psychiatry is not even practiced so it is not possible to even draw on clinical experience."¹⁵⁹ Patel et al note that in Zimbabwe, most persons suffering emotional distress consult both medical practitioners and traditional healers, but few

¹⁵¹ Gilborn et al (2006)

¹⁵² Bolton, P., personal communication (2006)

¹⁵³ Brown et al (2005)

¹⁵⁴ Gilborn et al (2006)

¹⁵⁵ USAID/Zambia, DCOF, SCOPE-OVC/Zambia and FHI. (2003) Findings of the Orphan and Vulnerable Children Survey.

¹⁵⁶ Thurman et al (2006)

¹⁵⁷ Bolton, P. (2001)

¹⁵⁸ Atwine et al (2005)

¹⁵⁹ Poulter, C. (1996) Vulnerable children: A psychological perspective. The Nordic Africa Institute, AIDS Orphans of Africa Project. (Available via OVC Toolkit website – Zambia.)

consult mental health specialists.¹⁶⁰ Soltani et al point out the inadequacy in developing countries of training of medical practitioners in mental health diagnosis and intervention, in research to create an evidence-base and in priorities and resources to address mental health issues in environments where conditions such as infectious diseases and malnutrition take center stage.¹⁶¹

In his study of psychopathology in Ethiopian children, Mulatu¹⁶² concurs that an understanding of child psychopathology has remained relatively unrecognized in developing countries. Health personnel and teachers are rarely able to identify children with problems, partly due to poor mental health training and large workloads. He cites a study by Giel et al in which only 15% of psychiatric cases were correctly identified by health workers. It is therefore difficult to gauge prevalence rates of mental disorders among children in developing countries, and how expected rates may vary in high stress contexts such as extreme poverty, political repression or conflict. Mulatu cites studies that have determined rates of child psychopathology in developing countries to be comparable to those in developed countries, with a range of approximately 14-20%.¹⁶³ Using the 10-item WHO Reporting Questionnaire for Children, Giel et al found rates ranging from 12-29% in Sudan, Philippines, India and Columbia¹⁶⁴ and Abiodun found similar high rates in Nigeria at 15% of 5-15 year olds identified with some form of psychopathology.¹⁶⁵ Other older studies determined rates to be between 8-20% in Sudanese villages¹⁶⁶ and 18% average (with a high of 24% in urban areas) for Ugandan school children.¹⁶⁷ His own study found rates of psychopathology in Ethiopian children aged 7-11 to be 23.2% using a culturally adapted CBCL and 27% using the WHO RQC. The methods and instruments used in determining prevalence rates clearly impact the findings, and Mulatu concludes that “To identify and treat child psychopathology, culturally valid measures of prevalence and risk factors need to be identified at the community level.”¹⁶⁸

5.3 Africa-Based Review: Methods and Findings

The methodologic and cross-cultural challenges described above should be kept in mind in the current literature review. All of the studies were conducted in Africa, and are

¹⁶⁰ Patel et al (2001)

¹⁶¹ Soltani, A., Moayyeri, A., and Raza, M. (2004) Impediments to implementing evidence-based mental health in developing countries. *Evidence-Based Mental Health*, 7: 64-66.

¹⁶² Mulatu, M. (1995) Prevalence and risk factors of psychopathology in Ethiopian children. *J Am Acad Child Adolesc Psychiatry*, 34 (1): 100-09.

¹⁶³ Bradenburg, N., Friedman, R., Silver, S. (1990) The epidemiology of childhood psychiatric disorders: Prevalence findings from recent studies. *J Am Acad Child Adolesc Psychiatry*, 29: 76-83.

¹⁶⁴ Giel, R., DeArango, M., Climent, C, et al. (1981) Childhood mental disorders in primary health care: results of observations in four developing countries. *Pediatrics* 68: 677-83.

¹⁶⁵ Abiodun, O. (1993) Emotional illness in a pediatric population in Nigeria. *J Trop Pediatr*, 39: 49-51.

¹⁶⁶ Cederbald, M. (1968) A child psychiatric study on Sudanese Arab children. *Acta Psychiatr Scand Suppl*, 44: 11-230.

¹⁶⁷ Minde, K. (1975) Psychological problems in Ugandan school children: a controlled evaluation. *J Child Psychol Psychiatry*, 16: 49-59.

¹⁶⁸ Mulatu (1995)

focused on the psychosocial well-being of orphaned and vulnerable adolescents. They are grouped into the following categories:

- 11 OVC surveys utilizing control/comparison groups of orphans and non-orphans
- 9 Other surveys of OVC
- 2 Psychosocial surveys of adolescents exposed to violence or war
- 5 Qualitative and descriptive studies

Appendix A provides comprehensive information on each study, including a description of the study, findings, survey instrument(s) or qualitative methods used, and psychometric properties of instruments where available. A summary of findings from each of group of studies is provided below.

5.3.1 Summary of Findings from Surveys Utilizing Control/Comparison Groups

Eleven studies used a control or comparison group in assessing psychosocial outcomes among orphans and other vulnerable children, including orphans due to causes other than AIDS, and non-orphans. Given the particular interest in the UNICEF Guide in discriminating as far as possible the particular psychosocial effects of orphaning and vulnerability due to HIV/AIDS, findings from these eleven studies are summarized on the following pages [see insert pages 36-37], and a discussion follows.

Summary of OVC Surveys Utilizing Control/Comparison Groups

Makame et al (2002):

Assessed 41 orphans aged 10-14 compared with 41 non-orphans in Tanzania using an adapted version of the Rand Mental Health and Beck Depression Inventories, as well as the Wide Ranging Achievement Test (scholastic achievement). Significant findings for orphans vs. non-orphans included:

- Markedly increased internalizing problems ($p<.0001$), increased suicidal ideation ($p=.016$), more likely to go to bed hungry ($p=.034$) and to be out of school ($p=.028$).
- Independent predictors of internalizing problems: female, going to bed hungry, no reward for good behavior, out of school, orphanhood.
- Note: 54% of entire sample reported physical punishment at school once or more in past week.

Cluver & Gardner (in press):

Assessed 30 orphans aged 7-19 compared to 30 non-orphans in Cape Town, SA, using the Strengths and Difficulties Questionnaire and the Impact of Events Scale (orphans only). Both groups scored highly for peer problems, emotional problems and total scores. No statistically significant differences on total SDQ or subscales; however individual item analysis showed significant findings for orphans vs. non-orphans:

- Less likely: have good friend ($p=.002$) or display anger through loss of temper ($p=.03$)
- More likely: difficulty concentrating ($p=.05$), somatic symptoms ($p=.05$), nightmares ($p=.01$)
- Note: 73% of orphans scored above cut-off for post-traumatic stress disorder.

Sengendo & Nambi (1997)

Assessed 193 orphans aged 6-20 compared to 24 non-orphans in Uganda using 20 questions from the Norwicki-Strickland Locus of Control Model and 25 questions on depression. Significant findings for orphans vs. non-orphans:

- Higher depression and lower optimism for future ($p<.05$)
- Even when material needs were met, orphans “did not function as well as expected.”

Atwine et al (2005)

Assessed 123 rural AIDS orphans aged 11-15 compared to 110 matched non-orphans in Uganda using the Beck Youth Inventory translated into Runyankore. Significant findings for orphans vs. non-orphans:

- More likely to be anxious, depressed and to display anger ($p<.001$)
- Significantly higher scores for orphans on individual BYI items particularly sensitive to depressive disorder: vegetative symptoms, hopelessness, suicidal ideation.
- No significant difference on Self-Concept.
- Orphan status only significant predictor of outcomes.

Chatterji et al (2005)

Assessed orphans compared with children living with chronically ill caregivers and “other children” in Rwanda and Zambia (N=1066 caregivers, 1160 children, 965 adolescents). Newly developed scales (adapted from various standardized scales) administered to children aged 6-12: worry/stress and responsibility/burden; and to adolescents aged 13-19: responsibility/burden and locus of control.

- Overall, orphans of all ages report more worry/stress, responsibility/overburden and poor locus of control than non-orphans, with children of ill caregivers reporting intermediate scores.
- Measures often correlated with household socioeconomic status and/or personal material possessions, and perceived community support/cohesion. Scores did not appear to differ by sex.

Poulter et al (1996)

Compared 22 households with orphans with 66 households with HIV+ parents and 75 control families in Zambia using caregiver reports on the Rutter’s Child Behavior Questionnaire. They were unable to interview children due to lack of privacy. Also assessed parent mental health status using the SRQ-20. No p-values are given, but the author reports the following significant findings:

- Unhappiness/worry: orphans > children with HIV+ parents > controls
- No clear link between psychological disturbance and economic stress
- No evidence of conduct disorders or anti-social behavior

- Parents with poor mental health significantly less likely to discuss their illness with children.
- No correlation between poor mental health status of parent and psychological disturbance in child.

Manuel et al (2002)

Assessed 76 orphans compared to 76 non-orphans, and their caregivers, in rural Mozambique. Significant findings for orphans vs. non-orphans included:

- Higher depression scores ($p < .001$)
- Less likely to have a trusted adult or friends ($p < .001$); more likely to be bullied ($p < .001$)
- Orphan caregivers report more depression ($p < .001$) and less social support than controls.

Wild et al (in press)

Assessed 81 AIDS orphans compared to 78 orphans from other causes and 43 non-orphans aged 10-19 in the Eastern Cape, South Africa using the R-CMAS, CDI, and items from the CBCL-YSR and SEQ. They also assessed psychological adjustment and its relation to certain moderating factors: emotional connection, behavioral regulation (adults, peers, neighborhood) and psychological autonomy. Significant findings:

- Depression/anxiety: “other” orphans > non-orphans ($p < .05$), with AIDS orphans falling between the two groups and not differing significantly from either
- Low self-esteem: “other” orphans > non and AIDS orphans
- Connection/regulation/autonomy in relationship with carer and connection/regulation with peers and neighborhood context significantly associated with better adjustment in orphans ($p < .001$)
- No group differences in externalizing problems (antisocial behavior)

Elmore-Meegan et al (analysis in progress)

Interviewed 956 children (average age 11) and their caregivers in 6 locations in Kenya, comparing orphans to children living with sick adults and to non-orphans (numbers not available). A multi-centre validation study of an adapted CBCL “to establish a sensitive scale for measuring behavior in OVC.”

Findings (p-values not given):

- Orphans significantly more depressed and stressed than non-orphans.
- Girls show more anxiety and dysfunction than boys.
- Other findings: orphans work more (especially girls) and are more malnourished (those attending school are less malnourished), orphans less likely to attend school.
- Over half of all children reported being physically punished in school in last month.

Nyamukapa et al (2006)

Factor analysis applied to 5,321 children aged 12-17 years from a 2004 cross-sectional national survey in Zimbabwe. Newly created psychosocial disorders and social connectedness scales. Significant findings:

- Orphans have more psychosocial disorders and more severe ps disorders for both sexes.
- Greater psychosocial disorders in girls, but no significant differences according to age.
- Orphanhood remained associated with psychosocial disorders after controlling for differences in poverty, sex/age of hh head, school enrolment, and support of closest adult and external sources.
- All orphans experienced depression, but few significant group differences in anxiety/self-esteem.
- Maternal and paternal orphans more likely to have started sex than non-orphans; being out of school and increased psychosocial disorder associated with early onset sexual activity.

Gilborn et al (2006)

Assessed 1,258 OVC aged 14-20 in Bulawayo, Zimbabwe, comparing participation in various community psychosocial support programs. Composite index variables created for: trauma, social support, daily stress, possessions. Significant findings:

- Orphans: more psychosocial distress, less psychosocial well-being. ($p < .05$ on specific items)
- Orphans: higher daily stress and lower social support scores ($p < .05$) regardless of gender.
- Females: higher mean trauma and daily stress scores, but also higher social support. ($p < .05$); significantly more psychosocial distress than males on 10 items. ($p < .05$)
- Older youth: higher trauma and daily stress scores, but also more confidence and self-esteem.

Adapted Scales and Psychometric Data

Most of the researchers utilized many different scales and subscales to capture psychosocial well-being constructs, pointing to the difficulty in finding one instrument or one set of concise measures to capture all of the domains of interest for emotional well-being, functioning, behavior and risk. Most studies used items selected from at least two standardized instruments, translated and adapted for local language and context, or created new survey instruments drawing from a wide variety of established measures. For example, Wild et al used select items or subscales from six established measures for life events, internalizing and externalizing problems (anxiety, depression, self-esteem, behavior) and additional measures – some drawn from the Social And Health Assessment (SAHA) scales¹⁶⁹ – for social relationships (peer, neighborhood and adult) to examine moderating factors such as perceptions of connection, behavioral regulation and psychological autonomy.¹⁷⁰

Psychometric data is available for instruments used in only five of the eleven studies. General psychometric data on standardized instruments is not provided here, although some studies reported this data for instruments that had been applied and “validated” in other developing countries. (See Balaban, in press, for psychometric data on psychological assessment instruments for children in disasters and emergencies.)¹⁷¹ However, given the significant modifications described to most instruments and the need for caution regarding conceptual validity of instruments described earlier, it would be essential to have validity and reliability data for the current instruments in order to make reasoned judgments about their usefulness.

The following studies reported alpha coefficients measuring internal consistency:

- Makame et al (2002): adapted Rand Mental Health and Beck Depression Inventories, alpha .83
- Atwine et al (2005): separate Beck Youth Inventory subscales, alpha .70-.85 (except disruptive behavior subscale, alpha .32); the separate inventories significantly inter-correlated except for self-concept which was not correlated with anxiety and anger.
- Chatterji et al (2005): newly created scales measured in Zambia (Z) and Rwanda (R)
 - child worry/stress scale, alpha .55 Z; .63 R
 - child overburden/responsibility scale, alpha .74 Z; .65 R
 - adolescent overburden/responsibility scale, alpha .61 Z; .43 R
 - adolescent locus of control scale, alpha .57 Z; .39 R
- Wild et al (in press): adapted RCMAS, alpha .8; CDI, alpha .64; SEQ, alpha .87; CBCL/YSR, alpha .47; CRPBI, alpha .91 (see table for psychometrics on other scales)
- Nyamukapa et al (2006): newly created psychosocial disorders scale, alpha .76, and social connectedness scale, alpha .78

Some adapted or newly created scales showed high internal consistency after translation to the local language and into adolescent’s vernacular. However, data from these studies cautions that subscales of standardized instruments should be analyzed separately for internal consistency (Atwine et al, 2005),¹⁷² and although psychometrics may be adequate

¹⁶⁹ Ruchkin, V., Schwab-Stone, M., Vermeiren, R. (2004) Social and health assessment (SAHA): Psychometric development summary. New Haven: Yale University.

¹⁷⁰ Wild et al (in press)

¹⁷¹ Balaban, V. (in press) Psychological assessment of children in disasters and emergencies. *Disasters*.

¹⁷² Atwine et al (2005)

in one country, it cannot be assumed one will achieve the same internal consistency in another country given substantial contextual, culture and linguistic differences (Chatterji et al, 2005).¹⁷³

Increased Internalizing Problems in Orphans

Results regarding psychosocial outcomes may be difficult to compare given the variety of instruments used in assessments, but the following findings for these case control studies are as follows. In all studies, statistically significant findings for increased internalizing problems (depression, anxiety, worry/stress) were found for orphans compared with non-orphans, or children living with HIV+ parents or sick adults. However, one study (Wild et al, in press), found that children orphaned by causes other than AIDS reported more depression and anxiety than non-orphans ($p < .5$), and lower self-esteem than both non-orphans and AIDS-orphans. AIDS orphans reports of depression and anxiety were intermediate between the two groups and not differing significantly from either. The authors speculate that because their sample of AIDS-affected adolescent orphans was recruited through non-governmental organizations, they were likely receiving services or other support which may have offered a protective effect on psychosocial outcomes, as compared with children orphaned by other causes.¹⁷⁴

In addition, Nyamakupa et al found that although all orphans experienced reported more psychosocial disorders (including depression) and of greater severity than non-orphans, there were few significant differences in anxiety or self-esteem between orphans and non-orphans.¹⁷⁵ Cluver and Gardner noted that both orphans and non-orphans scored highly for psychosocial distress and there were no statistically significant on total scale scores; however individual item analysis showed significantly more reports of somatic problems, difficulty concentrating, and displaying anger through loss of temper in orphans.¹⁷⁶ It is possible that the relatively small sample size in this study (30 orphans compared with 30 controls) was insufficient to detect a difference in total scores. Regardless, it is important to note that many studies found relatively high rates of depression, worry and stress among respondents, regardless of their status, emphasizing the vulnerability of all children in contexts of disadvantage.

Some studies reported significantly higher scores for orphans on items particularly sensitive to detecting depressive disorder, including vegetative symptoms, hopelessness and suicidal ideation.^{177 178 179} Regression analysis demonstrated in one study that orphanhood was the only significant predictor of outcomes of psychosocial disorder,¹⁸⁰

¹⁷³ Chatterji, M., Dougherty, L., Ventimiglia, T., Mulenga, Y., Jones, A., Mukaneza, A., Murray, N., Buek, K., Winfrey, W., and Amon, J. (2005) The well-being of children affected by HIV/AIDS in Gitarama Province, Rwanda and Lusaka, Zambia: Findings from a study. Community REACH Working Paper No.2, Washington, D.C.: Community REACH Program, PACT.

¹⁷⁴ Wild et al (in press)

¹⁷⁵ Nyamakupa

¹⁷⁶ Cluver & Gardner (in press)

¹⁷⁷ Atwine et al (2005)

¹⁷⁸ Gilborn et al (2006)

¹⁷⁹ Makame et al (2002)

¹⁸⁰ Atwine et al (2005)

and in another study that orphanhood was an independent predictor of internalizing problems.¹⁸¹ In a large study in Zimbabwe, orphanhood remained associated with psychosocial disorders after controlling for differences in poverty, sex and age of the head of household, school enrolment and support from the closest adult and external sources.¹⁸²

Lack of Evidence for Externalizing Behavior

Although not specifically measured in all studies, no evidence of increased externalizing behavior (antisocial or conduct problems) was found in any of the studies,^{183 184} consistent with Bray's assertion that predictions of large numbers of un-socialized and criminal orphaned youth emerging in Africa are without evidence.¹⁸⁵ It is important to note, however, that caregivers of children were interviewed in only three of the nine studies.^{186 187 188} Youth may have a tendency to under-report conduct problems on surveys and so caregivers may provide a more accurate assessment of externalizing behavior. On the other hand, caregivers tend to under-report internalizing distress in children.¹⁸⁹

In terms of risk behaviors, one study examined the relationship between onset of sexual activity and psychosocial well-being in OVC. Nyamukapa et al found that maternal and paternal orphans (although not double orphans) aged 12-17 were more likely to have started sex than non-orphans, and early onset of sexual activity was associated with two factors: being out of school, and increased psychosocial disorder.¹⁹⁰

More Psychosocial Distress in Girls

Gender differences were found in four studies with increased psychosocial disorder in girls as compared to boys. One study found being female to be an independent predictor of internalizing problems,¹⁹¹ and two others found greater psychosocial dysfunction and anxiety in girls.^{192 193} The fourth study assessing 1,258 OVC in Zimbabwe found that girls not only reported more psychosocial distress on specific items in the survey instrument, they also scored higher on composite indices for traumatic experiences and daily stress scores.¹⁹⁴

Traumatic Exposure and Daily Life Stress

¹⁸¹ Makame et al (2002)

¹⁸² Nyamukapa et al (2006)

¹⁸³ Poulter, C. (1996) Vulnerable children: A psychological perspective. The Nordic Africa Institute, AIDS Orphans of Africa Project. (Available via OVC Toolkit website – Zambia.)

¹⁸⁴ Wild et al (in press)

¹⁸⁵ Bray (2003)

¹⁸⁶ Manuel et al

¹⁸⁷ Poulter et al (1996)

¹⁸⁸ Elmore-Meegan et al (analysis in progress)

¹⁸⁹ Barnett, T. and Whiteside, A. (2002) AIDS in the twenty-first century: Disease and globalization. Palgrave MacMillian Ltd., Basingstoke.

¹⁹⁰ Nyamukapa et al (2006)

¹⁹¹ Makame et al (2002)

¹⁹² Elmore-Meegan et al (analysis in progress)

¹⁹³ Nyamukapa et al (2006)

¹⁹⁴ Gilborn et al (2006)

Overall, all youth in the aforementioned Zimbabwe study reported high levels of exposure to traumatic events and daily life stress, both increasing with age of the respondent. The authors also note that in their comparison of participation in psychosocial programs and psychosocial outcomes for youth, two factors were eliminated by regression analysis in the final model: time since exposure to death of a parent and orphan status. However, the trauma index (including exposure to illness and death among family and friends) and six other covariates remained (age, province, urban/peri-urban/rural setting, daily stress index and social support index). They speculate that although it's possible the surviving, extended family may have helped to fill the role of the deceased parent and mitigate the trauma of loss for youth, given the unusually high number of traumatic events and stressful conditions reported, it is more likely that the loss of a parent is one among many traumas faced by children and so didn't emerge as a singularly, exceptional traumatic event. They suggest that cumulative exposure to trauma and stress may be more important in influencing psychosocial outcomes.¹⁹⁵

Interestingly, only one study specifically measured post-traumatic stress symptoms. Cluver & Gardner administered the Impact of Events Scale to the 30 orphans in their sample (but not to controls) and found that 73% scored above the cut-off for post-traumatic stress disorder.¹⁹⁶ Although PTSD is highly co-morbid with anxiety and depression, current methods of assessing psychosocial distress may not be adequately capturing the traumatic effects of abuse, stigma, exploitation and high levels of daily stress.

Of concern in two studies were reports by over half of children of being physically punished in school – in the past month for children in Kenya,¹⁹⁷ and once or more in the past week for children in Tanzania.¹⁹⁸ There were no differences in these reports between orphans and non-orphans, but this highlights a potential area of exposure to abuse for children. Makame notes that high levels of corporal punishment in schools have been found in several studies in sub-Saharan Africa, and has been linked with “low self-esteem, poor school achievement, anxiety, depression, suicide, physical injuries and death in children.”¹⁹⁹

Chatterji et al's study of OVC in Rwanda and Zambia created a scale to measure children's and adolescents' sense of overburden and responsibility – similar to measures of daily life stress. Orphaned adolescents in both countries were significantly more likely to report high scores on this scale; orphaned children reported the highest scores in Zambia, whereas children of ill caregivers reported the highest scores in Rwanda. Higher socioeconomic status and/or material possessions, as well as an increased sense of community support, were protective against a sense of overburden and responsibility for both children and adolescents, worry and stress in children, and poor locus of control (or self-determination) in adolescents. (Note, given low internal consistency for measures

¹⁹⁵ Ibid.

¹⁹⁶ Cluver & Gardner (in press)

¹⁹⁷ Elmore-Meehan (analysis in progress)

¹⁹⁸ Makame et al (2002)

¹⁹⁹ Ibid.

applied to adolescents in Rwanda, the authors advise caution in interpretation of results.)²⁰⁰

Lack of Social Support for Orphans

Other studies also document the importance of social connection in a variety of spheres in relation to psychosocial outcomes. In their analysis of moderating factors, Wild et al found that “perceptions of connection, regulation and autonomy in the adolescent’s relationship with their caregiver, and experiences of connection and regulation in the peer and neighborhood contexts were associated with better adjustment in orphans.”²⁰¹

Makame et al also found that not having a reward for good behavior (as a caregiver or teacher may provide) was an independent predictor of internalizing problems in youth in Tanzania. Orphans in Zimbabwe reported significantly lower social support scores ($p < .5$) regardless of gender.²⁰² Cluver & Gardner found that orphans were more likely to report having no good friends ($p = .002$),²⁰³ and Manuel et al found that orphans were less likely to report having a good friend or trusted adult in their lives ($p < .001$) and more likely to report having been bullied by peers ($p < .001$) than non-orphans.²⁰⁴

Influence of Caregiver Psychopathology

General epidemiological surveys have consistently found that psychiatric disorder in either parent increases risk of psychopathology in children, and in particular, hostile or depressed mothers adversely affect the child’s functioning through dysfunctional social interactions. Studies have documented that poor mental health of the caregiver is an important risk factor for psychopathology in children.²⁰⁵ In their study of Ethiopian children, Mulatu et al reported that maternal psychopathology was the most important predictor of children’s psychopathology; psychopathology in children was 4.55 times more likely in children with a psychologically distressed mother and 1.7 times more likely in children from a high-stress family.²⁰⁶ However, the study by Poulter did not find a correlation between poor mental health status of parents and psychological disturbance in their children. They did, however, find that HIV-infected parents with poor mental health status were less likely to discuss their illness with their children.²⁰⁷

Although Mulatu demonstrated high inter-rater correlation of mother’s reports of their child’s mental health with a second informant close to the child, it has been shown in other studies that depressed caregivers are more likely to assess children in their care as psychologically distressed, as also demonstrated in the Rwanda study of youth heading households.²⁰⁸ Thus, if possible, the most accurate assessment of children’s emotional status and behavior should triangulate data from the child, caregiver and an objective observer.

²⁰⁰ Chatterji et al (2005)

²⁰¹ Wild et al (in press)

²⁰² Gilborn et al (2006)

²⁰³ Cluver & Gardner (in press)

²⁰⁴ Manuel et al (2002)

²⁰⁵ Mulatu (1995)

²⁰⁶ Ibid.

²⁰⁷ Poulter et al (1996)

²⁰⁸ Boris et al (in press)

Of note, Manuel et al found that caregivers of orphans were more likely to report depression and less social support for themselves than caregivers of non-orphans.²⁰⁹

Socio-economic Status and Psychosocial Outcomes

Findings on the impact of socio-economic status and psychosocial outcomes were mixed in these studies. Poulter et al found no clear link between psychological disturbance and economic stress in her study interviewing caregivers from 22 households with orphans, 66 households with HIV+ parents and 75 control families. However, Elmore-Meegan et al found that orphans are more malnourished and less likely to attend school (although those attending school are less malnourished),²¹⁰ and Chatterji et al found that measures of worry, overburden and poor locus of control in children and adolescents were often correlated with household socioeconomic status and/or material possessions.²¹¹

5.3.2 Other Surveys of OVC

Nine other studies are described in Appendix A. Seven of these studies surveyed OVC and/or their guardians and included information on psychosocial health. (Note that three analyses of the Rwanda study of youth heading households and children in their care are listed separately). One study evaluated the psychometric properties of the Self-Esteem Questionnaire (SEQ) among South African youth, and one study details clinical psychological interviews with 354 orphans in Democratic Republic of Congo. Many findings from these studies are detailed elsewhere in this paper, and a brief summary of main points only is provided here:

- Urban-rural differences among orphans in Zambia included higher reports of emotional disturbance in children separated from their siblings in urban areas ($p=.05$), and in children with more adults living in the caregiving family in rural areas ($p=.001$). An increased likelihood for school drop out was associated with being of older age in rural areas, and coming from a poor family in urban areas.²¹²
- Social marginalization was high among OVC in Rwanda, with older youth and girls reporting higher mistrust in relatives and/or community members. OVC also had strong perceptions of felt and enacted stigma.²¹³
- Non-orphaned vulnerable children were significantly more likely to be in school than orphans ($p<.000$) in Zambia.²¹⁴
- High rates of depression/ other psychological problems in OVC found:
 - Half of youth heading households in Rwanda met cutoff criteria for depression (significantly higher for girls); strongly correlated with social marginalization and moderately/strongly with lack of adult support.²¹⁵

²⁰⁹ Manuel et al (2002)

²¹⁰ Elmore-Meegan (analysis in progress)

²¹¹ Chatterji et al (2006)

²¹² Nampaya-Serpell (1998)

²¹³ Thurman et al (2006)

²¹⁴ USAID/Zambia SCOPE (2002)

- 89% of orphaned youth in Zambia “always or sometimes unhappy.”²¹⁶
- Clinical assessment of Congolese orphans identified 21% with “psychological troubles.” Of these, nearly 40% identified with “post-traumatic stress,” 34% with “affective troubles,” and 27% with “adaptation problems.”²¹⁷
- Of OVC aged 6-14 in Zimbabwe, 5% reported having engaged in sexual intercourse or had been sexually abused.²¹⁸

Psychometric data is provided for the evaluation of the Self Esteem Questionnaire (SEQ)²¹⁹ in South African youth. The SEQ is intended to measure multiple domains of self-esteem in youth and is comprised of six subscales assessing evaluations of the self in relation to five salient domains for this age group: peers, school, family, body image and sports/athletics. The authors conclude that “Results provided general support for the 6-factor structure proposed by DuBois et al (1996) and indicated that SEQ scores have good internal consistency and adequate test-retest reliability for English-speaking South Africans.” However, as described earlier (see section 5.2) the survey showed decreasing internal consistency as it was translated from English to Afrikaans to Xhosa. In addition, they note that seven of the items which had relatively low factor loadings and total-item correlations for all groups were reverse-score items, suggesting some youth may have simply answered according to a response set, or may have answered incorrectly due to fatigue.²²⁰ The clarity and ease of use of response scales for adolescents is important to keep in mind in design of national-level survey measures for this age group.

Psychometric data is also provided for the three analyses in Rwanda. The authors describe an in-depth qualitative process for gathering terms in the local language and ensuring cultural and context relevance of the survey instrument through an intensive, local technical review process. Internal consistency was found to be high for all scales used in the study including a newly developed social marginalization scale (alpha .78), available adult support scale (alpha .87) and grief scale (alpha .67), as well as an adapted version of the Center for Epidemiologic Studies-Depression (CES-D) scale²²¹ which incorporated some local terms from youth (alpha .84).^{222 223 224}

5.3.3 Psychosocial Surveys of Adolescents Exposed to Violence/War

²¹⁵ Boris et al (in submission)

²¹⁶ Volle et al (2002)

²¹⁷ Makaye, J., Mboussou, F., Bansimba, T., Ndinga, H., Latifou, S., Ambendet, et al. (2002) Assessment of psychological repercussions of AIDS next to 354 AIDS orphans in Brazzaville, 2001. Paper presented at the XIV International AIDS conference, Bracelona.

²¹⁸ Rusakaniko, S., Chingono, A., Mahati, S., Mupambireyi, P., and Chandiwana, B. (2006) Psychosocial conditions of orphans and vulnerable children in two Zimbabwean districts. HSRC, BRTI, NIHR & FACT, HSRC press.

²¹⁹ DuBois, D., Felner, R., Brand, S., Phillips, R. & Lease, A. (1996) Early adolescent self-esteem: A developmental-ecological framework and assessment strategy. *J of Research on Adolescence*, 6: 543-579.

²²⁰ Wild et al (2005)

²²¹ Chabrol, H., Montovany, A., Chouicha, K., Duconge, E. (2002) Study of the CES-D on a sample of 1,953 adolescent students. *Encephale*, 28(5 Pt 1): 429-432.

²²² Thurman et al (2006)

²²³ Boris et al (in submission)

²²⁴ Brown & Snider (analysis in progress)

Two studies are included in this review for adolescents exposed to violence or war, as both report psychometric data on scales used (including adapted standardized scales and new scales created from ethnographic research) and the findings add value to an understanding of trauma exposure and environmental risk also faced by many OVC.

Bolton et al's study in northern Uganda²²⁵ utilized the method described earlier of ethnographic research to develop a survey instrument in the local language (Luo) describing local syndromes of psychosocial distress in adolescents who had been exposed to conflict. The instrument was compared to the Strengths and Difficulties Questionnaire,²²⁶ and adequate and significant correlation was found between the two, including between subscales related specifically to emotional problems. Internal consistency was high for the local scale (alpha .91), and for the three subscales related to local syndromes (alpha .83-.84). The study found that 339 of 667 adolescents reported psychosocial distress warranting inclusion in a group therapy intervention, and six respondents were actively suicidal at the time of assessment.

Ward et al's study in a high violence community in Cape Town used several measures from the SAHA scales²²⁷ adapted to the local context, including exposure to community violence. Internal consistency generally ranged from .72 to .89 for most scales (conduct problems, conventional involvement, peer delinquency, parent support, future expectations and BASC anxiety and depression) except substance abuse (alpha .52), perceived competence for children (.64) and school support (alpha.69). A high level of violence exposure was reported in the sample, as the majority of children in the study (69%) reported both witnessing and being a victim of violence; and 28% reported only witnessing violence. Being a victim of violence was associated with both internalizing and externalizing disorders, and witnessing violence was associated with internalizing disorders. Details of significant associations in this study are:

- Violent victimization associated with depression, anxiety and conduct problems (p<.01)
- Witnessing violence associated with depression (p<.01) anxiety (p<.05)
- Peer delinquency associated with depression (p<.05) and conduct problems (p<.01)
- Involvement in conventional after-school activities negatively associated with anxiety (p<.01)
- School support negatively associated with depression (p<.05) and with conduct problems (p<.01)

Of note, there was no association between parent support and any resilience domains; and participants reported they were most likely to be victimized in their own homes. But the findings also suggest that a safe, supportive school environment may boost children's resilience against the impacts of exposure to violence.²²⁸

²²⁵Bolton, P., Betancourt, T., Bass, J., Speelman, L., Onyango, G. (2006) A Randomized Control Trial of Group Interpersonal Therapy and Creative Play for Psychosocial Problems in War-Affected Acholi Adolescents. World Vision, War Child and Boston University Report.

²²⁶ Goodman, R., Renfrew, D., Mullick, M. (2000) Predicting type of psychiatric disorder from Strengths and Difficulties Questionnaire (SDQ) scores in child mental health clinics in London and Dhaka. *European Child and Adolescent Psychiatry*, 9: 129-34.

²²⁷ Ruchkin et al (2004)

²²⁸ Ward et al (in submission)

5.3.4 Qualitative and Descriptive Studies

The five qualitative studies included in this review provide information on the situation of orphans and vulnerable children - including individual, family and community-level impacts and coping strategies - in Zimbabwe, Kenya and Uganda. Methods for gathering data included key informant interviews; focus groups with youth, their caretakers and community members; surveys; narratives; longitudinal household monitoring; and an orphan enumeration survey.

The orphan prevalence survey was conducted in and around Mutare, Zimbabwe, and found that 18.3% of households included orphans (12.8% single and 5% double orphans). There was a substantial increase in recent parental deaths, and 50% of parental deaths since 1987 could be attributed to AIDS.²²⁹ In the Uganda study, it was found that large numbers of orphans were overwhelming caregivers, with surviving family members often being too young or old, or too sick with AIDS themselves to care for the children.²³⁰ In Kenya, orphan caretakers described limited resources within the traditional, kinship-based support systems, and limited contribution from area community-based groups despite an exponential increase in orphan prevalence in the area.²³¹ The NGO response to the problem in Uganda was to set up local orphanages,²³² a move toward institutionalization rather than strengthening community and family systems.

In addition to lack of food, medicine, clothing and school fees, children and caregivers reported high levels of stigmatization and exploitation from family and community. Orphans' experiences of stigmatization from friends and community in Zimbabwe led to anxiety, fear, high levels of depression and stress, and problems at school.²³³ Focus group participants in Uganda noted that surviving widows are frequently stigmatized by the husband's family, so that the widow and her children are not "inherited" to be cared for by the deceased husband's brother (as is customary), and may even be accused of having killed her husband by witchcraft. Family members may steal the land and remaining resources from the widow, affecting the care of children in the household.²³⁴

²²⁹ Foster et al (1995)

²³⁰ Ntozi, J. & Mukiza-Gapere, J. (1995) Care for AIDS orphans in Uganda: findings from focus group discussions. *Health Transition Review*, 5 (Suppl): 245-52.

²³¹ Nyambedha, E., Wandibba, S., and Aagaard-Hansen, J. (2001) Policy implications of the inadequate support systems for orphans in western Kenya. *Health Policy*, 58 (1): 83-96.

²³² Foster et al (1995)

²³³ Ibid.

²³⁴ Ntozi & Mukiza-Gapere (1995)

6. Key Domains and Instrument Recommendations for Psychosocial Measures of Vulnerability~Resilience

Based on the review of literature and current evidence base outlined in this report, key domains for measuring the psychosocial well-being of OVC have emerged. The domains are included in measures on two separate survey instruments: one for youth self-report, and one for caregiver reports for triangulation of data. Brief measures on each domain are recommended after review of various, existing surveys which have been or are currently being tested in Africa. In addition, a draft youth survey was reviewed and tested with youth in Zimbabwe and South Africa, and with a draft caregiver survey was reviewed by caregivers in Zimbabwe. Findings from these focus groups are included in Appendix B, and have been incorporated into the final recommendations for measures (including wording, and preferences for alternative measures).

Key domains tap areas of personal, family and community/environmental sources of risk and protective factors for youth, in particular those factors that have been found to influence child psychosocial outcomes. The following table outlines the key domains in both surveys:

Caregiver Instrument	Youth Instrument
Caregiver report on: <ol style="list-style-type: none"> 1. Caregiver emotional health-seeking behavior 2. Caregiver exposure to domestic violence 3. Use of physical punishment or maltreatment in the home 4. Community maltreatment, exploitation, stigma and discrimination 5. Caregiver report of youth's emotional health (health-seeking behavior) 6. Caregiver report on youth's internalizing, externalizing and risk behaviors 	Youth self-report on: <ol style="list-style-type: none"> 1. Experience of stigma, discrimination and social exclusion 2. Social connection 3. Household violence, child abuse and corporal punishment 4. Exposure to community violence 5. Child work and responsibilities 6. Emotional health-seeking behavior 7. Externalizing and risk behavior 8. Internalizing problems, self-esteem, future orientation

Note that items 5 and 6 of the caregiver instrument, and items 6, 7 and 8 of the youth instrument all refer to the emotional health of the youth and can be considered under the larger heading of “psychosocial outcomes.” They encompass areas of importance to youth psychosocial functioning, including risk and externalizing behaviors, internalizing problems, self-esteem and a sense of future, in addition to health-seeking behavior as a gauge of severity of problems.

In reflecting upon recommendations from the previous consultative process for the development of these measures (see section 2), many recommendations have been incorporated, including the simplifying of response scales to ease use and improve comprehension, expansion of connectedness measures to incorporate social inclusion/exclusion beyond the primary caregiver (including elements of enabling vs.

stigmatizing environments for youth), and use of a theoretical framework of resilience and vulnerability in addition to child development theories. In particular, the recommendations from the UNICEF July 2005 consultation to capture domains relevant to the survival of children in conditions of severe deprivation or abuse are specifically addressed in household and community risk measures. Triangulation of data through the addition of caregiver reports has also been incorporated, although inclusion of direct observation should be considered in the future. Recommendations from the Bernard van Leer meeting to reduce the number of questions, simplify domains, and remove certain items pertaining to internalizing and externalizing behaviors were not supported by the literature. Although domains and measured constructs have certainly been clarified, the new framework adds additional domains critical to psychosocial outcomes. Items for internalizing problems are retained based on the literature, as well as some externalizing behaviors. Risk behaviors are also retained given their importance to youth outcomes and risk of HIV/AIDS infection in this age group.

The rationale for selection of each domain, description of the question, its source and reference are provided for each of the two instruments. In addition, special considerations in administering the instruments (sensitive questions, ethical issues) are examined. As recommended for the UNICEF psychological indicator, pilot testing and validation of terms in local languages is essential to enhance linguistic, cultural and contextual relevance of questions prior to wider administration of the instruments.

Pilot testing should also account for the understanding and relevance of questions to the ages and developmental stages represented in youth aged 12-17. Younger adolescents may differ markedly from older adolescents in physical and emotional maturity, life experience and expectations for capacities, responsibilities and behavior, as well as expressions of emotional distress. These differences may affect the measurement of psychosocial risk and capacity. For example, Atwine et al stratified youth into two age categories – ages 11-12 and ages 13-15 – for purposes of data analysis in the Uganda context.²³⁵ Also in Zimbabwe, questions about sexual behavior proved to be offensive to children aged 14.²³⁶ Pilot testing with youth in these different age ranges will help in determining suitability of questions according to developmental stage particular to each context.

In addition to the translatability of concepts, other issues should be considered in pilot testing and validation of recommended measures. Pilot testing of the psychosocial indicators in Jamaica showed that youth had difficulty with likert scales, and pictorial prompts were recommended. Other studies have also used pictorial prompts to increase comprehension and reduce response fatigue, particularly in younger respondents.^{237 238} The response mode itself may also need to be changed for cultural and linguistic comprehension of measures of frequency in time.

²³⁵ Atwine et al (2005)

²³⁶ Gilborn et al (2006)

²³⁷ Thurman et al (2006)

²³⁸ Bolton, P., & Tang, A. (2002) An alternative approach to cross-cultural function assessment. *Soc Psychiatry Psychiatr Epidemiol*, 37(11): 537-43.

Weighting of responses should be considered based on seriousness of particular items, such as suicidality.²³⁹ Recommendations are made for weighting and measuring of chronicity in certain domains in the caregiver and youth instruments, should this information be desired. Given that the measures proposed are often reduced items taken from standardized instruments, cut-off scores for detection of psychosocial disorder is not suggested at this time but is additionally an issue for pilot testing and validation of the instruments.

Of particular importance is attention to the sensitive nature of questions related to abuse, risk behavior and depressive and suicidal feelings. For both caregivers and youth, these questions may be difficult to handle. We therefore recommend that the final instrument contains a few short questions of an everyday and non-threatening nature prior to proceeding with the questions that are the main focus of this survey instrument. In addition, it is essential that respondents be interviewed in private, in a place where they feel most comfortable, both to protect the confidentiality of their responses, minimize potential for retribution by others and to improve quality of data.

As there is the potential for re-traumatization of respondents during the interview process as they reveal sensitive information, utmost care should be taken in the training of interviewers and in informed consent procedures. Although this information will be stated in the informed consent, respondents should be reminded at the outset of administering these instruments that they may find some questions upsetting, they do not have to answer any question they do not want to, and they can stop or suspend the interview anytime they like. It is essential that support and referral resources be established prior to commencement of the instrument, and in determining obligations for reporting and protection of children from harm (abuse, suicidality and other grave impairment). As is currently stated in the UNICEF Guide, Ethical Guidelines developed by USAID and the Population Council's Horizons Project should be followed in gathering information from children and adolescents.²⁴⁰

²³⁹ Makame et al (2002)

²⁴⁰ Schenk, K. and Williamson, J. (2005) Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guidelines and Resources. Population Council, Washington, D.C.

6.1 Caregiver Instrument: Domains, Rationale and Suggested Items

Domain 1: Caregiver’s Emotional Health-Seeking Behavior

Rationale: The stability and emotional health of parents is an important determining factor of psychosocial outcomes in children.

Question: This is a newly created question based on various existing studies of health seeking behaviors in cross-cultural settings. Research evidence shows that a range of paths to healing are sought in all communities. (Desjarlais et al, 1995) The ones mentioned in the question are most typical of a range of African contexts. A similar question has been used by Brandt et al (analysis in progress) with HIV positive caregivers in South Africa. The questions below have been modified based on focus group findings with caregivers of HIV-affected children in rural Zimbabwe. The initial question frames psychological distress in locally recognizable terms. The subsequent question measures severity of distress by the need to seek assistance from a recognized healer.

Question 1	Source	Reference								
<p>1.1 When the times are very difficult, people can feel very sad or unhappy. They can also feel that life is a struggle that is too big for them, or they can feel spiritually or emotionally troubled. When things are difficult they can also feel pain in their bodies like headaches or stomachaches. When this happens, many people with children feel they need to be strong for the children. In the past year have you felt like this...</p> <table border="1" style="margin-left: auto; margin-right: auto;"> <tr> <td style="text-align: center;">3</td> <td style="text-align: center;">2</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td style="text-align: center;"><i>Every week</i></td> <td style="text-align: center;"><i>At least once a month</i></td> <td style="text-align: center;"><i>Only sometimes</i></td> <td style="text-align: center;"><i>Not at all</i></td> </tr> </table>	3	2	1	0	<i>Every week</i>	<i>At least once a month</i>	<i>Only sometimes</i>	<i>Not at all</i>	<p>No direct source. Constructed for this instrument from various sources including the work of Brandt (2006), South Africa</p>	<p>Kleinman and Sung (1979); Kleinman (1988); Goldberg and Huxley (2003); Desjarlais et al (1995); Kleinman, 1988; Bracken et al (1995); Swartz (1998)</p>
3	2	1	0							
<i>Every week</i>	<i>At least once a month</i>	<i>Only sometimes</i>	<i>Not at all</i>							
<p>1.2 In the last year, have you felt so spiritually or emotionally troubled that you felt you needed to* consult a healer (spiritual healer, faith healer or traditional healer), counselor or health worker (clinic nurse or doctor)?</p> <table border="1" style="margin-left: auto; margin-right: auto;"> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td style="text-align: center;"><i>Yes</i></td> <td style="text-align: center;"><i>No</i></td> </tr> </table>	1	0	<i>Yes</i>	<i>No</i>						
1	0									
<i>Yes</i>	<i>No</i>									

* Please answer according to whether or not you felt you needed to consult someone, even if you were not able to get there because of distance, cost or other reasons.

Alternative wording: an alternative to question 1.2 (using the same binary response scale) is also suggested for pilot testing based on Brandt’s (2006) experience in South Africa. “In the last year, have you had a psychological problem for which you consulted a healer (spiritual healer, faith healer or traditional healer), counselor or health worker (clinic nurse or doctor)?” The use of more direct terms for psychological problems and the actual consultation of a healer may be more clearly understood as clinically significant distress by respondents.

Domain 2: Caregiver Exposure to Domestic Violence

Rationale: Domestic violence is a serious risk to children’s psychosocial well-being, and stability and well-being of caregivers. It is an important factor affecting risk and protective factors in families and households. It is likely to occur more often in households under severe strain (Dawes et al, 2006).

Question: One item selected from DHS survey for South Africa 1998, with minor modifications from the Conflicts Tactics Scales (Strauss et al, 1996) (inclusion of the phrase “that could hurt” in reference to something thrown at any adult in the house, not just the respondent). Note that the scoring system normally used in the Conflict Tactics Scales is not recommended for the present instrument as it is complex and may not produce reliable information. The Scales are normally scored on a five-point system (0-4) as follows:

0	1	2	3	4
Never	Once or twice	3-5 times	6-10 times	>10 times

For present purposes we have used time periods (weekly, monthly, less often, never) as research on exposure to violence in other studies in South Africa using a similar measure (but not the CTS) shows that inaccuracies are likely when participants are asked to estimate the number of times an event has occurred. (Brandt et al, 2005)

Question 2	Source	Reference												
<p>2.1 Over the past year, has anyone in the household kicked, bitten, slapped, hit with a fist, threatened with a weapon (knife, stick or gun), or thrown something that could hurt at another adult who lives here?</p> <div style="text-align: center;"> <table border="1"> <tr> <td>1</td> <td>0</td> </tr> <tr> <td>Yes</td> <td>No</td> </tr> </table> </div> <p>2.2 If yes, how often does this happen?</p> <div style="text-align: center;"> <table border="1"> <tr> <td>3</td> <td>2</td> <td>1</td> <td>0</td> </tr> <tr> <td>Weekly</td> <td>Monthly</td> <td>Less often</td> <td>Never</td> </tr> </table> </div>	1	0	Yes	No	3	2	1	0	Weekly	Monthly	Less often	Never	DHS	1998 DHS for South Africa
1	0													
Yes	No													
3	2	1	0											
Weekly	Monthly	Less often	Never											

Domain 3: Use of Physical Punishment or Maltreatment in the Home

Rationale: Child abuse (evidence by use of harsh physical punishment) in the home is a serious risk to children’s psychosocial well-being. According to Strauss (2000, p. 1113), corporal punishment is a risk factor for child physical abuse, but regardless of whether it escalates into physical abuse, “bringing children up violently puts [them] at a higher risk for the development of many social and psychological problems.” This is also recognized in the UN Study of Violence Against Children (<http://www.crin.org/violence/>). See also the meta-analytic review by Gershoff (2003).

Special Issues: There is inevitably under-reporting of child abuse by caregivers, which can be as low as 5% of the incidence (Hooper, 2002). In order to cross-check findings, youth will also report on their exposure to violence in the home on the youth survey. It is imperative that respondents (caregivers and youth) are asked these questions privately, not in the presence of other persons/possible abusers, in order to obtain more accurate information and protect the respondent from retribution.

Question: Two alternatives are given. For both alternatives, the caregiver is asked to respond about the use of the discipline practice to any child in the household - not specifically to a certain child or the child who will be filling out the youth instrument – in order to best understand the context of violence toward children in the home and to enhance the likelihood of accurate responses.

Alternative I is derived from the Parent-Child Conflict Tactics Scales (Straus et al, 1998) and asks about different approaches to discipline, including non-violent, psychological aggression and directly violent approaches. Note that the original response for h) is worded “Took away privileges or “grounded” him/her.” As the term “grounded” is a particular term in the US for non-violent discipline and may not be understood, alternative wording is suggested for clarity in African and other contexts. [Depending on the time of administration and length of overall instrument, additional questions are suggested for use under each of the three headings in blue font.](#)

Alternative II is a more comprehensive option which as a result contains more items. They are derived from the ICAST-P, a measure of parent/caregiver child discipline techniques. Selection of this question provides synergy between the UNICEF national-level indicator work and the UN Study of Violence against children. (permission to draw on these items was granted by the ISPCAN project team).

Six items were selected from ICAST-P designed to detect severe forms of violence to children. An item that does not involve direct violence "Threatened to invoke ghosts or evil spirits, or harmful people" is also included as it reflects an important form of punishment likely to be used in African settings. (This item may stand alone in factor analysis of survey data, and is scored separately.) In addition, one response for non-violent discipline is offered as an appropriate discipline strategy.

Scoring:

“Past year” rather than “life prevalence” is used as it is most proximal to the time of the OVC survey and therefore more relevant to the impacts of HIV on youth. Scoring is based on that used in the Conflict Tactics Scales. This is because the ICAST-P scoring system had not been finalized at the time of writing (personal communication, Adam Zolotor, July 2006):

- **Past year prevalence of caregiver violence to a child:** *the proportion of caregivers reporting one or more acts of violence to a child in the past year* (utilizing the direct-violence items). Score = 1 if any item is endorsed; Score = 0 if no items are endorsed.
- **Past year prevalence of use of threats of harm to a child:** *the proportion of caregivers reporting one or more threats of harm to a child in the past year* (utilizing the non-direct violence item). Score = 1 if any item is endorsed; Score = 0 if no items are endorsed.

Question 3, alternative I	Source	Reference
<p>In the past year, how often have you or another adult in the household used this method of discipline with any child in your household...</p> <p>Direct violence:</p> <p>a) Used a stick, belt, hairbrush or other hard item to discipline your child?</p> <p>b) Slapped, punched or hit your child on his/her head or face?</p> <p>Psychological aggression:</p> <p>c) Said you would send him/her away or kick him/her out of the house?</p> <p>d) Threatened to invoke ghosts or evil spirits, or harmful people against the child?</p> <p>e) Withheld a meal to punish him or her?</p> <p>f) Called him or her dumb, lazy or other names like that?</p> <p>Non-violent discipline:</p> <p>g) Explained to your child why something they did was wrong?</p> <p>h) Took away privileges or stopped him/her from going out</p>	<p>CTS, revised measure tested in the US and other countries.</p> <p>Items d) and e) are from ICAST and item f) is from Straus, so as to align completely with the child questions below.</p>	<p>Straus et al (1998)</p>

<p>with friends, or stopped other activities like playing sport to teach him/her a lesson?</p> <table border="1" data-bbox="370 289 755 373"> <tr> <td>3</td> <td>2</td> <td>1</td> <td>0</td> </tr> <tr> <td><i>Weekly</i></td> <td><i>Monthly</i></td> <td><i>Less often</i></td> <td><i>Never</i></td> </tr> </table> <p><i>Past year prevalence score 1 if any item endorsed, 0 if never.</i></p>	3	2	1	0	<i>Weekly</i>	<i>Monthly</i>	<i>Less often</i>	<i>Never</i>		
3	2	1	0							
<i>Weekly</i>	<i>Monthly</i>	<i>Less often</i>	<i>Never</i>							
<p>Question 3, alternative II</p>	<p>Source</p>	<p>Reference</p>								
<p>All adults use certain methods to teach children the right behavior or to address a behavior problem. I will read various methods that might be used and I want you to tell me how often you (or if applicable, your husband/partner) have used this with any of your children <u>in the last year</u>. Tell me if you [or your husband/partner] have done this with any child: never; once or twice; three to five times; six to ten times; or more than 10 times in the last year.</p> <p>Non-violent discipline:</p> <ul style="list-style-type: none"> a) Explained why something was wrong? b) Took away privileges or money, forbade something liked or prohibited him/her from leaving the home? <p>Psychological aggression:</p> <ul style="list-style-type: none"> c) Threatened to invoke ghosts or evil spirits, or harmful people? d) Threatened to kick out of the house or send away for a long time? e) Withheld a meal as punishment? f) Insulted [name of child] by calling him/her dumb, lazy or other names like that? <p>Direct violence:</p> <ul style="list-style-type: none"> g) Hit him/her on the buttocks with an object such as a stick, broom, cane or belt? h) Hit elsewhere (not on buttocks) with an object such as a stick, broom, cane or belt? i) Hit him/her on head with knuckle or back of the hand? j) Kicked him/her with a foot? k) Hit him/her over and over again with object or fist (“beat up”)? l) Threatened him/her with a knife or gun? m) Slapped on face or back of head? <table border="1" data-bbox="370 1539 755 1623"> <tr> <td>3</td> <td>2</td> <td>1</td> <td>0</td> </tr> <tr> <td><i>Weekly</i></td> <td><i>Monthly</i></td> <td><i>Less often</i></td> <td><i>Never</i></td> </tr> </table> <p><i>Past year prevalence score 1 if any item endorsed, 0 if never.</i></p>	3	2	1	0	<i>Weekly</i>	<i>Monthly</i>	<i>Less often</i>	<i>Never</i>	<p>Parent Questionnaire: Punishment, Discipline and Violence in the Home (ICAST-P)</p>	<p>International Society for the Prevention of Child Abuse and Neglect (IPSCAN), 2006.</p>
3	2	1	0							
<i>Weekly</i>	<i>Monthly</i>	<i>Less often</i>	<i>Never</i>							

Domain 4: Community Maltreatment, Exploitation, Stigma & Discrimination

Rationale: The maltreatment (abuse or exploitation) of children in the community captures serious risk to children’s safety and well-being, as it relates to social exclusion and vulnerability to various forms of abuse.

Question: The question is adapted from a scale used in a survey of mentors serving youth-headed households in Rwanda. Seven of nine questions from the original survey are recommended, and respondents are asked how the community feels about “children affected by AIDS” rather than “orphans.” The original scale uses a 5-point agree/disagree response which we have adapted to a binary response. For purposes of brevity, two items have been combined from the original survey to create item a). The first three items are suggested for inclusion (a, b, and c) as they tap actual behaviors related to stigma and discrimination (enacted stigma). **Depending on length of survey and time for administration, the last three items are additionally suggested for inclusion (d, e and f) in blue font as they further elaborate community attitudes and beliefs that may explain accepting or rejecting behaviors.**

Question 4	Source	Reference				
<p>How does this community feel about children whose parents have HIV/AIDS?</p> <p>a) Adults in this community are generally concerned for the welfare of these children, and help them as much as they can.</p> <p>b) The community rejects these children.</p> <p>c) These children are more likely to be hurt (maltreated or taken advantage of) than helped by people in this community.</p> <p>d) The community feels these children carry with them the bad deeds of their parents.</p> <p>e) The community feels these children cause problems in the neighborhood/village.</p> <p>f) People in this community make fun of or talk bad about these children.</p> <div style="text-align: center;"> <table border="1"> <tr> <td>1</td> <td>0</td> </tr> <tr> <td>Yes</td> <td>No</td> </tr> </table> </div>	1	0	Yes	No	<p>Rwanda study “Mentor survey” (analysis in progress, internal consistency not yet established but has been high for other measures created for this study)</p>	<p>Brown and Snider (analysis in progress)</p>
1	0					
Yes	No					

Domain 5: Caregiver Report of Youth’s Emotional Health (Health-Seeking Behavior)

Rationale: Parents tend to under-report children’s internalizing emotional problems, while emphasizing “naughty” behavior (that may also be a sign of emotional distress); however, in any community, the need to consult an authority (medical, faith healer, counselor or traditional healer) indicates serious concern for children’s psychosocial health.

Question: This is a newly created question based on various studies of child and adult representations of psychological distress in poorer African communities, including somatic representations, local idioms of distress and behavioral problems in children. Based on these studies, the question has face validity. In addition, references to health-seeking behaviors of adults may also apply in seeking assistance for an ill child (see source and references, question 1 above).

Question 5	Source	Reference
<p>In the last year, has your child been so mentally, spiritually or emotionally troubled* that you felt you needed** to take them to a healer (spiritual healer, faith healer or traditional healer), counselor or health worker (clinic nurse or doctor)?</p>	<p>No source, constructed for this instrument.</p>	<p>Dawes and Cairns, (1998), Reynolds, (1997)</p>

	1	0		
	Yes	No		

* For example, sad, having problems with nerves, often complaining of headaches or stomach aches, or being much more disobedient than usual?

** Please answer according to whether or not you felt you needed to consult someone, even if you were not able to get there because of distance, cost or other reasons.

Alternative wording: an alternative to question 6 (see explanation for question 1.2 above) is also offered: "In the last year, has your child had a psychological problem for which you consulted a healer (spiritual healer, faith healer or traditional healer), counselor or health worker (clinic nurse or doctor)?"

Domain 6: Caregiver Report on Youth's Internalizing, Externalizing and Risk Behaviors

Rationale: This question reflects caregivers' assessment of psychosocial health of youth in key areas of internalizing, externalizing problems, social functioning, problem-solving skills and pro-social behavior. Of note, caregiver report of externalizing and risk behaviors are likely to be more accurate than youth self-report. Adolescent depression has been found to be associated with an increased risk of depression in adulthood, and in conjunction with conduct problems may be particularly associated with severe outcomes. (Fombonne et al, 2001)

Question: 10-item caregiver scale adapted from the Strengths and Difficulties Questionnaire (SDQ).

Question 6	Source	Reference
Emotional symptoms subscale (3 of 5 items) <ul style="list-style-type: none"> a) Often complains of headaches, stomachaches or sickness. (somatization) b) Often unhappy, downhearted or tearful. (internalizing problems, depression) c) Nervous or clingy in new situations, easily loses confidence. (self-esteem) 	SDQ	Goodman et al (2000), Bolton et al (2006)
Conduct problems subscale (3 of 5 items) <ul style="list-style-type: none"> d) Generally obedient, usually does what adults request. (social values) e) Often fights with other children, bullies them. (externalizing behavior) f) Steals from home, school or elsewhere. (externalizing, antisocial) 		
Peer problems subscale (2 of 5 items) <ul style="list-style-type: none"> g) Has at least one good friend. (peer connection) h) Picked on or bullied by other children. (peer connection, stigma) 		
Hyperactivity subscale (1 of 5 items) <ul style="list-style-type: none"> i) Thinks things out before acting. (problem-solving, life skills) 		
Pro-social subscale (1 of 5 items) <ul style="list-style-type: none"> j) Considerate of other people's feelings - for example, is helpful if someone is hurt, upset or feeling ill.* (compassion) 		

2	1	0		
<i>Certainly true</i>	<i>Somewhat true</i>	<i>Not true</i>		

*Note: the example added to take account of the specific circumstances of the HIV context.

Caregiver Survey References

Brandt, R. (2006) "I'm HIV+, I'm poor and I care for young children." An investigation of the caregiving and psychological well-being of low socio-economic status others and women caregivers in the era of HAART. Instruments developed and validated for Doctoral Research, Department of Psychology, University of Cape Town.

Brandt, R., Ward, C., Dawes, A., and Flisher, A. (2005) Epidemiological measurement of children's and adolescent's exposure to community violence: Working with the current state of the science. *Clinical Child and Family Psychology Review*, 9: 328-43.

Bolton, P., Betancourt, T., Bass, J., Speelman, L., Onyango, G. (2006) A Randomized Control Trial of Group Interpersonal Therapy and Creative Play for Psychosocial Problems in War-Affected Acholi Adolescents. World Vision, War Child and Boston University Report.

Bracken, P., Giller, J. and Summerfield, D. (1995) Psychological responses to war and atrocity: The limitations of current concepts. *Social Science and Medicine*, 40: 1073-82.

Brown and Snider (analysis in progress) See Brown, L., Thurman, T., and Snider, L. (2005) Strengthening the psychosocial well-being of youth-headed households in Rwanda: Baseline findings from an intervention trial. *Horizons Research Update*, Population Council: Washington, D.C.

Dawes, A. and Cairns, E. (1998) The Machel study: Dilemmas of cultural sensitivity and universal rights of children. *Peace and Conflict: Journal of Peace Psychology* 4 (4): 335-48.

Dawes, A., de Sas Kropiewnicki, Z., Kafaar, Z. And Richter, L. (2006) Partner violence. In U. Pillay, B. Roberts and S. Rule (Eds.), *South African Social Attitudes: Changing times, diverse voices.* (pp. 225-51) Cape Town: HSRC Press.

Desjarlais, R., Eisenberg, L., Good, B. and Kleinman, A. (1995) *World mental health: Problems and priorities in low income countries.* New York: Oxford University Press.

DHS: South African Demographic and Health Survey. (1998) Pretoria: Department of Health.

Fombonne, E., Wostear, G., Cooper, V., Harrington, R., and Rutter, M. (2001) The Maudsley long-term follow-up of child and adolescent depression: Psychiatric outcomes in adulthood. *British Journal of Psychiatry*, 179: 210-7.

Gershoff, E. (2003) Corporal punishment by parents an associated child behaviors and experiences: A meta-analytic and theoretical review. *Psychological Bulletin*, 128: 539-79.

Goldberg, D. and Huxley, P. (2003) *Mental illness in the community: The pathway to psychiatric care.* London: Routledge.

Goodman, R., Renfrew, D., Mullick, M. (2000) Predicting type of psychiatric disorder from Strengths and Difficulties Questionnaire (SDQ) scores in child mental health clinics in London and Dhaka. *European Child and Adolescent Psychiatry*, 9: 129-34.

Hooper, C. (2002) Maltreatment of children. In J. Bradshaw (Ed.), *The wellbeing of children in the UK*. (pp. 103-121) London: Save the Children, UK.

Kleinman, A. and Song, L. (1979) Why do indigenous practitioners successfully heal?: A follow-up study of indigenous practice in Taiwan. *Social Science and Medicine*, 130: 7-26.

Kleinman, A. (1988) *Rethinking Psychiatry: From cultural category to personal experience*. New York: The Free Press.

Reynolds, P. (1997) *Children and traditional healing in Zimbabwe*. Ohio University Press: Athens, Ohio.

Straus, M., Hamby, S., Finkelhor, D., Moore, D. and Runyan, D. (1998) Identification of child maltreatment with the Parent-Child Conflict Tactics Scales: Development and psychometric data for a national sample of American parents. *Child Abuse and Neglect*, 22: 249-70.

Strauss, M., Hamby, S., Boney McCoy, S. and Sugarman, D. (1996) The revised Conflict Tactics Scale (CTS2): Development and preliminary psychometric data. *Journal of Family Issues*, 17: 283-316.

Swartz, L. (1998) *Culture and mental health: A Southern African view*. Cape Town: Oxford University Press.

6.2 Youth Survey: Domains, Rationale and Suggested Items

Demographic Questions

If these questions have not already been asked of youth respondents, we recommend that they are placed here prior to administration of this instrument, both for purposes of information gathering and as examples of non-threatening questions to precede the following which are of a more sensitive nature.

Demographic Questions
<i>Interviewer tick gender of respondent: boy _____ or girl _____</i> How old are you?.....years _____ months _____ Are you enrolled in school?.....yes _____ no _____ If yes, what grade/class (use local term) are in this year (now)?.....grade _____


Domain 1: Experience of Stigma, Discrimination, and Social Exclusion

Rationale: This question fills a gap in the stigma/discrimination indicator of community attitudes by capturing the child’s experience of stigma and social exclusion.

Question: Two alternatives are given.

Alternative 1 is adapted from a scale used in a survey of youth-headed households in Rwanda. The original scale uses a 5-point agree/disagree response which we have adapted to a binary response. We would also suggest testing of a 3-point response scale: “how much do you feel...none/a little/a lot.” This alternative is offered given its high internal consistency with youth in Rwanda.

Alternative 2 contains questions aligned with those asked of caregivers (domain 4, caregiver instrument) which would allow for direct comparison of caregiver and youth responses. Although similar to questions in alternative 1, the internal consistency of these items is still in analysis and they have not been used with adolescents previously. As in the caregiver instrument, the first three items are suggested for inclusion (a, b, and c), and depending on length of survey and time for administration, the last three items are additionally suggested for inclusion (d, e and f) in blue font as they further elaborate community attitudes and enacted stigma.

Question 1, alternative I	Source	Reference
Do you feel... (a) People in this community reject children who have AIDS or whose caregivers have AIDS? (b) No one cares about you in this community? (c) You are isolated from others in this community? (d) People in this community would rather hurt you than help you? (e) People speak badly about you or your family? (f) People make fun of your situation? 	Rwanda survey alpha .758	Boris et al (in review) Thurman et al, 2005

Question 1, alternative II		
<p>How does this community feel about children whose parents have HIV/AIDS?</p> <p>a) Adults in this community are generally concerned for the welfare of these children and help them as much as they can.</p> <p>b) The community rejects these children.</p> <p>c) These children are more likely to be hurt (maltreated or taken advantage of) than helped by people in this community.</p> <p>d) The community feels these children carry with them the bad deeds of their parents.</p> <p>e) The community feels these children cause problems in the neighborhood/village.</p> <p>f) People in this community make fun of or talk bad about these children.</p>	<p>Rwanda study “Mentor survey” (analysis in progress, internal consistency not yet established but has been high for other measures created for this study)</p>	<p>Brown and Snider (analysis in progress)</p>



Domain 2: Social Connection

Rationale: Although desirable that the child’s source of support is to a caregiver that they live with, many children do not have a primary caregiver in the home or could identify such a person in their lives. This question therefore measures whether or not they have a *person* (peer, other adult or caregiver) that provides them support in these areas.

Question: Two alternatives are given.

Alternative I is a newly created brief 3-item question tapping critical areas of social connection, with items drawn from the Rwanda study of youth-headed households. The 5-point agree/disagree scale has been adapted to a binary scale. Focus groups with youth in Zimbabwe and South Africa revealed that these questions were salient to their daily life stressors and needs.

Alternative II is the recommended brief version of the UNICEF Connection to Caregiver indicator utilizing 6 items related to Support and Provision of Resources (Guide, p. 40). Existing instructions ask the respondent to identify an adult with whom they spend the most time living with. Recognizing that many children are living without adult support, we suggest that the adolescent instead identifies a “person” with whom they spend considerable time – or “someone in your life that you rely on/that you can depend on” for these questions. In addition, based on focus group discussions with youth in South Africa and Zimbabwe, the word “necessities in 3.1.d. is changed to “needs.” Note that youth in focus groups indicated difficulty in distinguishing “hardly ever” from “not at all” in the response scale, especially when translated into the vernacular.

Question 2, alternative I	Source	Reference
<p>Do you have someone in your life you can depend on...</p> <p>(a) For advice and guidance?</p> <p>(b) To go with you to the clinic, schools or social service agency if you needed help?</p> <p>(c) To comfort you when you feel sad or sick?</p>	<p>Rwanda scale 3 of 4 items, (4-item scale, alpha .87)</p>	<p>Boris et al (in submission)</p>

<table border="1" style="margin-left: auto; margin-right: auto;"> <tr> <td style="padding: 2px;">1</td> <td style="padding: 2px;">0</td> </tr> <tr> <td style="padding: 2px;">Yes</td> <td style="padding: 2px;">No</td> </tr> </table>	1	0	Yes	No								
1	0											
Yes	No											
Question 2, alternative II	Source	Reference										
<p>Think of someone in your life you can depend on. How often does that person...</p> <p>(a) Comfort me? (b) Have open communication with me? (c) Trust me? (d) Provide for me needs? (e) Give me money? (f) Buy me things?</p> <table border="1" style="margin-left: auto; margin-right: auto; width: 100%;"> <tr> <td style="text-align: center;">4</td> <td style="text-align: center;">3</td> <td style="text-align: center;">2</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td style="text-align: center;"><i>Very often</i></td> <td style="text-align: center;"><i>Often</i></td> <td style="text-align: center;"><i>Sometimes</i></td> <td style="text-align: center;"><i>Hardly ever</i></td> <td style="text-align: center;"><i>Not at all</i></td> </tr> </table>	4	3	2	1	0	<i>Very often</i>	<i>Often</i>	<i>Sometimes</i>	<i>Hardly ever</i>	<i>Not at all</i>	Barber Short Scale, revised	UNICEF Guide (2005); Barber (2004)
4	3	2	1	0								
<i>Very often</i>	<i>Often</i>	<i>Sometimes</i>	<i>Hardly ever</i>	<i>Not at all</i>								

Domain 3: Household Violence, Child Abuse and Corporal Punishment

Rationale: Family violence and child abuse/corporal punishment are critical risk factors for children’s well-being at household level.

Special Issues: The sensitivity of questions on domestic violence, child abuse and corporal punishment necessitate special training for interviews in asking these questions and on responsibilities for referral for child respondents who are at current risk of harm. Support and referral resources should be established for this survey if these questions are to be asked. In focus groups, youth did not indicate that this line of questioning was particularly upsetting and they did feel they were important items in relation to risks to their well-being.

Furthermore, these questions should only be asked of youth in private, without the caregiver or other adult present, in order to increase the likelihood of accurate responses and protect the respondent from retribution.

Question: As suggested by youth in focus groups, this question first asks whether or not the youth has a guardian or adult living in the household, to make this relevant for child-headed households. If yes, the respondent is asked items from the Straus Conflict Tactics Scale (P-C CTS). Straus et al (1998) note that the instrument can be used in interviews with adolescent populations. In addition, two items (e and f) are taken from the ICAST-P as to align with the caregiver instrument. Scoring is based on the CTS system (see description in caregiver instrument) rather than the more complex ICAST-P system, as this is more appropriate for adolescent populations. (Brandt et al, 2005)

Note that the last item, “keeps you out of school,” is an additional item added at the suggestion of youth in focus groups but would need to be tested and validated for consistency with the other items, and with the scoring system.

Question 3	Source	Reference				
<p>3.1 Do you have an adult or guardian in your home who looks after you?</p> <table border="1" style="margin-left: auto; margin-right: auto;"> <tr> <td style="padding: 2px;">1</td> <td style="padding: 2px;">0</td> </tr> <tr> <td style="padding: 2px;">Yes</td> <td style="padding: 2px;">No</td> </tr> </table>	1	0	Yes	No	<p>Straus P-CTTS</p> <p>Item are drawn from various subscales including the ‘non-violent discipline,’ ‘severe assault, and psychological aggression’ subscales.</p>	<p>Straus et al (1998)</p>
1	0					
Yes	No					

<p>3.2 If yes, How often do adults in your home...</p> <p>(a) Shout at each other? (b) Hit each other?</p> <table border="1" style="margin-left: 40px;"> <tr> <td style="text-align: center;">3</td> <td style="text-align: center;">2</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td style="text-align: center;"><i>Weekly</i></td> <td style="text-align: center;"><i>Monthly</i></td> <td style="text-align: center;"><i>Less often</i></td> <td style="text-align: center;"><i>Never</i></td> </tr> </table> <p>3.3 If yes, in the past year, how often do your guardian(s)...</p> <p>(a) Take time to explain why something you do is wrong? (b) Use a stick, belt, hairbrush or other hard item to discipline you? (c) Slap, punch or hit you on your head or face? (d) Said you would be sent away or kicked out of the house? (e) Threatened to invoke ghosts or evil spirits, or harmful people? (f) Withheld a meal to punish you? (g) Insulted you by calling you dumb, lazy or other names like that? (h) Kept you out of school?</p> <table border="1" style="margin-left: 40px;"> <tr> <td style="text-align: center;">3</td> <td style="text-align: center;">2</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td style="text-align: center;"><i>Weekly</i></td> <td style="text-align: center;"><i>Monthly</i></td> <td style="text-align: center;"><i>Less often</i></td> <td style="text-align: center;"><i>Never</i></td> </tr> </table> <p><i>Past year prevalence score 1 if any item endorsed, 0 if never.</i> <i>For chronicity measures, use weighting in table.*</i></p>	3	2	1	0	<i>Weekly</i>	<i>Monthly</i>	<i>Less often</i>	<i>Never</i>	3	2	1	0	<i>Weekly</i>	<i>Monthly</i>	<i>Less often</i>	<i>Never</i>		
3	2	1	0															
<i>Weekly</i>	<i>Monthly</i>	<i>Less often</i>	<i>Never</i>															
3	2	1	0															
<i>Weekly</i>	<i>Monthly</i>	<i>Less often</i>	<i>Never</i>															

*See explanation for measuring chronicity in caregiver survey, question 4.

Domain 4: Exposure to Community Violence

Rationale: Exposure to community violence, both victimization and witnessing, have demonstrated consequences for youth psychosocial outcomes. This question taps environmental risks.

Question: Two items of victimization and witnessing of community violence from the DHS are used.

Question 4	Source	Reference								
<p>How often have you...</p> <p>(a) Been attacked outside your home (b) Seen someone stabbed, beaten or shot outside your home?</p> <table border="1" style="margin-left: 40px;"> <tr> <td style="text-align: center;">3</td> <td style="text-align: center;">2</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td style="text-align: center;"><i>Weekly</i></td> <td style="text-align: center;"><i>Monthly</i></td> <td style="text-align: center;"><i>Less often</i></td> <td style="text-align: center;"><i>Never</i></td> </tr> </table>	3	2	1	0	<i>Weekly</i>	<i>Monthly</i>	<i>Less often</i>	<i>Never</i>	DHS	1998 DHS for South Africa
3	2	1	0							
<i>Weekly</i>	<i>Monthly</i>	<i>Less often</i>	<i>Never</i>							

Domain 5: Child Work and Responsibilities

Rationale: This question distinguishes common child work roles to more critical child risks of being out of school due to household responsibilities or begging/child labor.

Question: Items are derived from the Survey of Activities of Young People (Statistics for South Africa). Similar questions are included in child labor surveys as recommended by the International Labor Organization.

Question 5	Source	Reference												
<p>6.1 In the past year, did you ever have to stay out of school to attend to household duties? (fetching water/ wood, tending animals, working on the land, caring for younger children or sick adults, or getting money to support the household, etc)</p> <table border="1" style="margin-left: auto; margin-right: auto;"> <tr> <td>1</td> <td>0</td> </tr> <tr> <td>Yes</td> <td>No</td> </tr> </table> <p>6.2 If yes, how often does this happen?</p> <table border="1" style="margin-left: auto; margin-right: auto;"> <tr> <td>3</td> <td>2</td> <td>1</td> <td>0</td> </tr> <tr> <td>Weekly</td> <td>Monthly</td> <td>Less often</td> <td>Never</td> </tr> </table>	1	0	Yes	No	3	2	1	0	Weekly	Monthly	Less often	Never	Survey of Activities of Young People	Burdlinger and Bosh (2002) Statistics South Africa (1999 and 2000)
1	0													
Yes	No													
3	2	1	0											
Weekly	Monthly	Less often	Never											

Domain 6: Emotional Health-Seeking Behavior

Rationale: Somatic representations of depression and anxiety can easily be expressions of real physical illness (i.e., gastroenteritis – stomach pain, fatigue, lack of energy, poor sleep, digestive problems). In the absence of a screen for physical health, it is risky to assume these things would indicate emotional disorder, especially in a relatively healthy population of young people. For this reason, standard adult instruments for screening psychiatric disorders are not appropriate given cross-cultural issues regarding somatization, and no reference to actual illness. In addition, the length of most standard screening instruments (GHQ has 20 items) is too long for our short screen.

Question: The question below is newly created to tap emotional distress of *such a severity* that the respondent seeks outside assistance. See Caregiver Instrument, Domain 1, for further explanation of cultural references. A similar question has been used by Brandt et al (analysis in progress) in South Africa.

Question 6	Source	Reference				
<p>In the last year, have you been so mentally, emotionally or spiritually troubled that you felt you needed to* consult a healer (traditional or spiritual healer) or health worker (clinic nurse or doctor)?</p> <table border="1" style="margin-left: auto; margin-right: auto;"> <tr> <td>1</td> <td>0</td> </tr> <tr> <td>Yes</td> <td>No</td> </tr> </table>	1	0	Yes	No	No direct source. Constructed for this instrument from various sources, including the work of Brandt et al (analysis in progress)	Reynolds, (1997)
1	0					
Yes	No					

*Please answer according to whether or not you felt you needed to consult someone, even if you were not able to get there because of distance, cost or other reasons.

Alternative wording: an alternative to question 1 (see explanation for question 1.2 on caregiver instrument) is also offered: “In the last year, have you had a psychological problem for which you consulted a healer (spiritual healer, faith healer or traditional healer), counselor or health worker (clinic nurse or doctor)?”

Domain 7: Externalizing and Risk Behavior

Rationale: Substance abuse, antisocial behavior and criminality are potential outcomes for at-risk children which critically impact their psychosocial well-being, functioning and longer-term development. Note: children tend to under-report externalizing behavior, so caregiver report is also captured in caregiver instrument.

Question: Select items from SAHA scales summarizing externalizing and risk behaviors including substance abuse, delinquency and violence. SAHA scales have been used in South Africa, among other countries.

Question 7	Source	Reference
During the past year, how many times (if any) have you... (a) Been drunk or very high from using alcoholic beverages or using drugs (marijuana, [insert local terms], etc)? (b) Been arrested by the police for your behavior? (c) Threatened someone seriously or beaten up somebody? <div style="border: 1px solid black; display: inline-block; padding: 2px;">5+ 3-4 2 1 0</div>	SAHA 55 (b), 65 (v) and 65 (s) respectively, used in South Africa	Ruchkin et al (2004)

Domain 8: Internalizing Problems, Self-Esteem, Future Orientation

Rationale: It is important to measure children's report of internalizing problems, as these are typically under-reported by caregivers, and have been shown to be a consequence of the impact of orphaning and vulnerability due to HIV/AIDS.

Special Issues: Each alternate question contains an item related to suicidality. When asking these questions, it is essential that interviewers receive training on asking questions about suicidality sensitively and to be able to assess respondents' current risk of self-harm. A referral and support mechanism must be in place for respondents who indicate active suicidal ideation.

Question: This question is adapted from the CDI (Child Depression Inventory). The question on appearance was found to be offensive/sad for youth in focus groups in Zimbabwe and South Africa and so has been removed. Question on suicide used here per Wild & Flisher, 2006. An advantage of these items is that they capture both positive and negative outcomes within each response, and cover several domains within one brief survey: self-esteem, self-efficacy, internalizing problems, future orientation, peer relationships and general social connectedness.

Question 8	Source	Reference
This part of the questionnaire looks at sadness and other difficulties which people may experience at some point in their lives. The questionnaire is arranged in groups of 3 statements. Please listen to each group carefully. Then pick out ONLY ONE statement from each group which best describes the way you have been feeling during the last 2 weeks... a) I am sad once in a while; I am sad many times; I am sad all the time. b) Nothing will ever work out for me; I'm not sure if things will work	CDI 11 items, (alpha 6.4 for 10-item questionnaire)	Wild et al, 2006

<p>out for me; Things will work out for me OK.</p> <p>c) I do most things OK; I do many things wrong; I do everything wrong.</p> <p>d) I hate myself; I do not like myself; I like myself.</p> <p>e) I do not think about killing myself; I think about killing myself but I f) would not do it; I want to kill myself.</p> <p>g) I feel like crying everyday; I feel like crying many days; I feel like crying once in a while.</p> <p>h) Things bother me all the time; Things bother me many times; Things bother me once in a while.</p> <p>i) I do not feel alone; I feel alone many times; I feel alone all the time.</p> <p>j) I have plenty of friends; I have some friends but wish I had more; I don't have any friends.</p> <p>k) Nobody really loves me; I'm not sure if anybody loves me; I'm sure that somebody loves me.</p>		
---	--	--

Youth Survey References

Barber, B. (2004) Report to UNICEF on: The connection with adult caregiver tool statistical analyses of data from adolescents in Malawi and Jamaica. University of Tennessee.

Boris, N., Thurman, T., Snider, L., Spencer, E. and Brown, L. (in review) Infants and young children living in youth-headed households in Rwanda: Implications of emerging data. *Infant and Mental Health Journal: Culture and Infancy Special Issue*.

Brandt, R., Ward, C., Dawes, A., and Flisher, A. (2005) Epidemiological measurement of children's and adolescent's exposure to community violence: Working with the current state of the science. *Clinical Child and Family Psychology Review*, 9: 328-43.

Burdlinger, D. and Bosh, D. (2002) South Africa Child Domestic Workers: A national report. Prepared for the International Labor Organization Programme on the Elimination of Child Labour (IPEC), May.

DHS: South African Demographic and Health Survey. (1998) Pretoria: Department of Health.

Reynolds, P. (1997) Children and traditional healing in Zimbabwe. Ohio University Press: Athens, Ohio.

Ruchkin, V., Schwab-Stone, M., Vermeiren, R. (2004) Social and health assessment (SAHA): Psychometric development summary. New Haven: Yale University.

Statistics South Africa (1999 and 2000) Questionnaires used in the Survey of Activities of Young People in South Africa.

Straus, M., Hamby, S., Finkelhor, D., Moore, D. and Runyan, D. (1998) Identification of child maltreatment with the Parent-Child Conflict Tactics Scales: Development and psychometric data for a national sample of American parents. *Child Abuse and Neglect*, 22: 249-70.

Thurman, T., Snider, L., Boris, N., Kalisa, E., Nkunda Mugarire, E., Ntaginara, J. And Brown, L. (2006) Psychosocial support and marginalization of youth-headed households in Rwanda. *AIDS Care*, 18 (3): 220-9.

UNICEF (2005) Guide to Monitoring and Evaluation of the National Response for Children Orphaned and Made Vulnerable by HIV/AIDS.

Wild, L., Flisher, A., Laas, S., and Robertson, B. (2006) The psychosocial adjustment of adolescents orphaned in the context of HIV/AIDS. *The Journal of Child and Adolescent Mental Health*, 13 (1).

7. Conclusion

As a contribution to the ongoing process of refining psychological measurement through population-based surveys and national-level indicator development, this activity has reviewed the literature to date on the impacts of HIV/AIDS on psychosocial well-being outcomes for orphans and other vulnerable children, with a focus on Africa-based studies and instruments. A set of short measures (many drawn from existing surveys used or currently being tested in Africa settings) have been recommended to obtain data on child vulnerability and resilience as follows:

The child's context as measured by:

1. Caregiver emotional health
2. Exposure to domestic violence
3. Exposure to harsh punishment or supportive discipline
4. Exposure to support or maltreatment at home and in the community (including exposure to stigma and community violence)
5. Child work
6. Social connectedness

The impact on the child's emotional health as assessed by:

1. Extent of internalizing problems
2. Extent of externalizing problems and risk behavior

In effect, this instrument provides two indicators: an indicator of contextual risk, and an indicator of whether there is a resilient or vulnerable outcome. In further analysis, it would be desirable to test the contribution of each context item to the child outcome measures, using appropriate statistical procedures. Once this has been done, the instrument would need to be modified and simplified in order to include only the context domains that are most powerful in predicting the child outcomes. This would also permit a final step of deriving one "contextual risk indicator score" and one "child emotional health score" derived similarly from the relevant items in the instrument.

The key domains of vulnerability and resilience provided here intend to encompass the critical areas of psychological well-being, resilience and social inclusion for orphans and other vulnerable children in high risk conditions. It is our hope that this contribution will help to move forward a process of monitoring the status and capacity of these children at national level to survive, and further to thrive and achieve their full potential.

References

Atwine, B., Cantor-Graaea, E., and Bajunirweb, F. (2005) Psychological distress among AIDS orphans in rural Uganda. *Social Science and Medicine* 61: 555-64.

Bolton, P., Betancourt, T., Bass, J., Speelman, L., Onyango, G. (2006) A Randomized Control Trial of Group Interpersonal Therapy and Creative Play for Psychosocial

Problems in War-Affected Acholi Adolescents. World Vision, War Child and Boston University Report.

Boris, N., Thurman, T., Snider, L., Spencer, E., and Brown, L. (in review) Infants and Young Children Living in Youth-Headed Households in Rwanda: Implications of Emerging Data. *Infant Mental Health Journal: Culture and Infancy Special Issue*.

Brown, L., Thurman, T. and Snider, L. (2005) Strengthening the Psychosocial Well-being of Youth-Headed Households in Rwanda: Baseline Findings from an Intervention Trial. *Horizons Research Update*, Population Council: Washington, DC.

Chatterji, M., Dougherty, L., Ventimiglia, T., Mulenga, Y., Jones, A., Mukaneza, A., Murray, N., Buek, K., Winfrey, W., and Amon, J. (2005) The well-being of children affected by HIV/AIDS in Gitarama Province, Rwanda and Lusaka, Zambia: Findings from a study. Community REACH Working Paper No.2, Washington, D.C.: Community REACH Program, PACT.

Cluver, L. and Gardner, F. (in press) The psychological well-being of children orphaned by AIDS in Cape Town, South Africa. *Annals of General Psychiatry*.

Dubois, D., Felner, R.D., Brand, S., Phillips, R.S.C. & Lease, A.M. (1996). Early adolescent self-esteem: A developmental-ecological framework and assessment strategy. *Journal of Research on Adolescence*, 6: 543-579

Elmore-Meegan, M., Tomkins, A., Conroy, R., Achenbach, P., Nyambati, W, Reid, T., et al. (2006) Identifying vulnerable children: Interim results of the adapted Achenbach child behavioural scale: Institute of Child Health, London.

Foster, G., Makufa, C., Drew, R, Mashumba, S., and Kambeau, S. (1997) Perceptions of children and community members concerning the circumstances of orphans in rural Zimbabwe. *AIDS Care* 9 (4): 391-405.

Foster, G., Shakespeare, R., Chinemana, F. Jackson, H., Gregson, S., Marange, C., and Mashumba, S. (1995) Orphan prevalence and extended family care in a peri-urban community in Zimbabwe. *AIDS Care*, 7 (1): 3-17.

Gilborn, L., Apicella, L., Brakarsh, J., Dube, L., Jemison, K., Kluckow, M., Smith, T. and Snider, L. (February 2006) Orphans and Vulnerable Youth in Bulawayo, Zimbabwe: An Exploratory Study of Psychosocial Well-being and Psychosocial Support Programs. *Horizons/Population Council Report in conjunction with REPSSI and CRS Strive*.

Makame, V., Ani, C., Grantham-McGregor, S. (2002) Psychological wellbeing of orphans in Dar Es Salaam, Tanzania. *Acta Paediatr* 91 (4): 459-65.

Makaye, J., Mboussou, F., Bansimba, T., Ndinga, H., Latifou, S., Ambendet, et al. (2002) Assessment of psychological repercussions of AIDS next to 354 AIDS orphans in

Brazzaville, 2001. Paper presented at the XIV International AIDS conference, Bracelona.

Manuel, P. (2002) Assessment of orphans and their caregivers' psychological well-being in a rural community in central Mozambique. Unpublished MSc, Institute of Child Health, London.

Nampaya-Serpell, N. (1998) Children orphaned by HIV/AIDS in Zambia: Risk factors from premature parental death and policy implications. Unpublished PhD, University of Maryland, Baltimore.

Ntozi, J. & Mukiza-Gapere, J. (1995) Care for AIDS orphans in Uganda: findings from focus group discussions. *Health Transition Review*, 5 (Suppl): 245-52.

Nyambedha, E., Wandibba, S., and Aagaard-Hansen, J. (2001) Policy implications of the inadequate support systems for orphans in western Kenya. *Health Policy*, 58 (1): 83-96.

Nyamukapa, C., Gregson, S., Lopman, B., Saito, S., Watts, H., Monasch, R. and Jukes, M. (2006) HIV-associated orphanhood and children's psychosocial disorders: Theoretical framework tested with data from Zimbabwe. Biomedical Research and Training Institute Harare, Imperial College London and UNICEF Zimbabwe.

Poulter, C. (1996) Vulnerable children: A psychological perspective. The Nordic Africa Institute, AIDS Orphans of Africa Project. (Available via OVC Toolkit website – Zambia.)

Rusakaniko, S, Chingono, A., Mahati, S., Mupambireyi, P., and Chandiwana, B. (2006) Psychosocial conditions of orphans and vulnerable children in two Zimbabwean districts. Biomedical Research and Training Institute and National Institute of Health Research of the Ministry of Health and Child Welfare (Harare, Zimbabwe), & FACT. HSRC Press.

Sengendo, J. and Nambi, J. (1997). The psychological effect of orphanhood: a study of orphans in Rakai district. *Health Transition Review* 7 (Suppl): 105-24.

Thurman, T., Snider, L., Boris, N., Kalisa, E., Nkunda Mugarire, E., Ntaginara, J. and Brown, L. (2006) Psychosocial Support and Marginalization of Youth-Headed Households in Rwanda. *AIDS Care*, 18(3): 220-9.

USAID/Zambia, DCOF, SCOPE-OVC/Zambia and FHI. (2002) Results of the Orphans and Vulnerable Children Head of Household Baseline Survey in Four Districts in Zambia.

Volle, S., Tembo, S., Boswell, D, Bowsky, S., Chiwele, D., Chiwele, R., et al (2002) Psychosocial baseline survey of orphan and vulnerable children in Zambia. Paper presented at the XIV International AIDS conference, Barcelona.

Walker, L. (2002) 'We will bury ourselves;' A study of child-headed households on commercial farms in Zimbabwe. Harare, Zimbabwe: Farm Orphan Support Trust of Zimbabwe.

Wild, L.G., Flisher, A.J., Bhana, A. & Lombard, C. (2005) Psychometric properties of the self-esteem questionnaire for South African adolescents. *South African Journal of Psychology*, 35: 195-208.

Wild, L., Flisher, A., Laas, S. and Robertson, B. (in press) The psychosocial adjustment of adolescents orphaned in the context of HIV/AIDS. *The Journal of Child and Adolescent Mental Health*, 13 (1).

Wolff, P. and Gebremeskel, F. (1999) The orphans of Eritrea: a five-year follow-up study. *Journal of Child Psychology and Psychiatry*, 40 (8); 1231-7.

Appendices:

A) Review of Africa Based Studies (table)

B) Focus Group Findings

Appendix A: Review of Africa-Based Studies

OVC Surveys Utilizing Control/Comparison Groups of Orphans and non-Orphans

Study Description	Findings	Instruments	Validity/Reliability
Tanzania: Makame et al (2002)			
<p><u>Compared 41 AIDS orphans aged 10-14 with 41 non-orphans</u> from poor suburbs of Dar es Salaam. (HIV-infected and orphans due to other causes excluded).</p> <p>Assess psychological well-being, possible environmental stressors (experiences of punishment, reward and hunger) and arithmetic ability.</p> <p>Note: 54% of entire sample reported being physically punished at school once or more in past week.</p>	<p>Significant findings orphans vs. non-orphans:</p> <ul style="list-style-type: none"> -markedly increased <u>internalizing problems</u> ($p < .0001$) -more likely to have contemplated <u>suicide</u> (34%) ($p = .016$) vs. 12% non-orphans -more likely to go to bed <u>hungry</u> ($p = .034$) and be <u>out of school</u> ($p = .028$) <p>Independent predictors of internalizing problems: female sex, going to bed hungry, no reward for good behavior, out of school, orphanhood. Receiving praise/reward for good behavior reduced internalizing problems.</p> <p>No difference orphans vs. non-orphans in physical punishment/praise/reward at home or school.</p>	<p><u>Rand Mental Health and Beck Depression Inventories</u></p> <p>-21 item questionnaire adapted from the above, translated into Swahili and adapted to children's vernacular</p> <p><u>Wide Ranging Achievement Test</u> (school achievement)</p>	<p>Alpha .83</p> <p>N/A</p>
South Africa: Cluver and Gardner (in press)			
<p><u>Compared 30 orphans aged 7-19 with 30 non-orphans</u> in Cape Town metro area.</p> <p>Note: Impact of Events Scale was given only to the orphan group; 73% scored above the cut-off for <u>post-traumatic stress disorder</u></p>	<p>Both groups scored highly for peer problems, emotional problems and total scores.</p> <p>No stat significant differences on total SDQ score or any subscales.</p> <p>However, significant findings for orphans on individual item analysis:</p> <ul style="list-style-type: none"> -less likely: have good friend ($p = .002$), or to display anger through loss of temper ($p = .03$) 	<p><u>Strengths and Difficulties Questionnaire</u> (pro-social behavior, conduct, peer connection, externalizing and internalizing behavior)</p> <p><u>Impact of Events Scale</u> (post-traumatic stress disorder)</p>	<p>Not available for this study, but author notes scaling for IES changed from 4-point to 3-point following Winje and Ulvike (1998) who report Cronbach's alpha: intrusion=.72, avoidance=.75, and (1991) intrusion=.79, avoidance.34.</p>

	-more likely: difficulty concentrating (p=.05), somatic symptoms (p=.05), constant nightmares (p=.01)		
Uganda: Sengendo & Nambi (1997)			
<u>Compared 193 orphans aged 6-20 with 24 non-orphans</u> in WV educational sponsorship (systematic random sampling from all eligible sponsored youth). Methods: In-depth interviews; survey; guardians and teachers interview (school performance linked with home observation); Focus groups: teachers, orphans, Parish Committee Members	Significant findings orphans vs. non-orphans: -higher depression scores (p<.05) -lower optimism for future (p<.05) Psychosocial problems may be related to findings that orphans did not function as well as expected even when material needs were met. Children confronted with an ill parent felt sad and helpless, and upon adoption, many felt angry and depressed. (Atwine, 2005)	Instrument created from <u>Norwicki-Strickland Locus of Control Model</u> (20 questions) and 25 questions to measure levels of depression	Not available
Uganda: Atwine et al (2005)			
<u>Compared 123 rural AIDS orphans aged 11-15 and 110 matched non-orphans.</u> Note: Multivariate analysis of current and past living conditions found <u>orphan status to be the only significant predictor of outcomes.</u> Also, depression higher in orphans living in smaller vs. larger households.	Significant findings orphans vs. non-orphans: -more anxiety (OR=6.4), depression (OR=6.6) and anger (OR=5.1) (p<.001) -no differences in Self-Concept Orphans scored significantly higher on items particularly sensitive to childhood depressive disorder: -hopelessness (think life will be bad p<.001) -suicidal ideation (wish you were dead p<.01) -vegetative symptoms (trouble sleeping p<.001; stomach hurts p<.001)	<u>Beck Youth Inventory</u> Self-report instrument across five inventories of 20 questions each (self-concept, anxiety, depression, anger and disruptive behavior). Translation into Runyankore and back-translation, as well as pre-testing.	Validity not assessed. Internal consistency for separate BYI inventories satisfactory (alpha .70-.85) except for Disruptive Behavior (alpha .32). Separate inventories significantly inter-correlated, except for Self-Concept which was not correlated with Anxiety and Anger (p=.08 and .07, respectively)
Rwanda, Zambia: Chatterji et al (2005)			
<u>Compared orphans, children with chronically</u>	<u>Child Worry/Stress</u>	New scales developed adapting	

<p><u>ill caregivers and non-affected children aged 6-12 and 13-19</u> in Rwanda and Zambia. Sample interviewed: Primary caregivers: 496 (Z), 570 (R) Children 6-12: 504 (Z), 656 (R) Adolescents 13-19: 563 (Z), 402 (R)</p> <p>Worry/Stress scale measured for children aged 6-12. High worry/stress measured by agreement on 5 or more questions. Overall, higher SES and perceived community support associated with less worry.</p> <p>Overburden/Responsibility scale measured for children aged 6-12 and adolescents aged 13-19. High sense of responsibility/overburden measured by agreement on 3 or more questions. Overall, less sense of burden correlated with higher SES (R) and perceived community support associated in children, and older age in adolescents.</p> <p>Locus of Control scale measured for adolescents aged 13-19. Poor locus of control (or self-determination) measured by agreement on 3 or more questions. Overall, females, older adolescents, more community cohesion, higher SES and material possessions reported more positive sense of control</p>	<p>-Zambia: orphans>children with ill caregivers> other children (p=.04) -Rwanda: orphans and children with ill caregivers> other children (p=.03) -Rwanda: worry/stress scores correlated with SES (p=.03) and community cohesion (p<.001).</p> <p><u>Child Overburden/Responsibility</u> -Highest burden: orphans (Zambia), children of ill caregivers (Rwanda) (p=.01 in R, non-significant in Z) -Not correlated with age, sex or material possessions -Significant correlations with community cohesion (p<.001 in Z/R), and with SES (p<.001 in R).</p> <p><u>Adolescent Overburden/Responsibility</u> -Orphans>other groups -Zambia: correlated with material possessions (p=.005) -Rwanda: correlated with age (p<.001), material possessions (p<.001) and comm cohesion (p=.03) -No correlation with sex; older feel less burdened than younger adolescents</p> <p><u>Adolescent Poor Locus of Control</u> -Orphans>children with ill caregivers>other children (p<.001 in R, non-significant in Z) -Correlated with age (p=.007), sex (p=.04), SES (p<.001) -R/Z: correlated with comm cohesion (p<.001), material possessions (p<.001)</p>	<p>questions from several established instruments. All used a 3-point scale</p> <p><u>Child Version (age 6-12):</u></p> <p>Worry/Stress Scale (7 items) Overburden/Responsibility (4 items)</p> <p><u>Adolescent Version (age 13-19):</u></p> <p>Overburden/Responsibility (4 items) Locus of Control (4 items)</p>	<p>Good convergent validity suggesting both scales measure underlying construct of well-being. Pearson's: Zambia r=.32, p<.001; Rwanda: r=.43, p<.001</p> <p>Alpha .55 Zambia; Alpha .63 Rwanda Alpha .74 Zambia; Alpha .65 Rwanda</p> <p>Good convergent validity between the two scales in Zambia: r=.1, p=.00 and adequate internal consistency; but low internal consistency of scales in Rwanda:</p> <p>Alpha .61 Zambia, Alpha .43 Rwanda Alpha .57 Zambia, Alpha .39 Rwanda</p> <p>Results for adolescents in Rwanda should be interpreted with caution given low internal consistency of measures.</p>
<p>Zambia: Poulter et al (1996)</p>			

<p>Orphan study assessed <u>22 households with orphans</u> in Lusaka (44 orphans total).</p> <p>Family study assessed <u>66 households with HIV+ parents and 75 control families</u> in same area in Lusaka</p> <p>Also assessed physical status of children (height and weight) and mental health status of adults in Family Study.</p> <p>Note: Focus groups found that orphaned children or children of sick parents described being “chased from school” b/c of lack of money for uniforms/fees. Also reported being beaten at school.</p>	<p>“Significant” findings (p-values not reported):</p> <ul style="list-style-type: none"> -orphans more likely to be unhappy and worried than children with HIV+ parents who were more likely to be unhappy, worried, solitary and fearful of new situations than children in control families. <p>Other findings:</p> <ul style="list-style-type: none"> -No clear link between psychological disturbance in children and economic stress. -No evidence conduct disorders or anti-social behavior in children. -No correlation between orphan status and “stunting,” but half of all children studied were below fifth percentile on height charts. -Poorer mental health in HIV+ adults than controls and parents with poor mental health significantly less likely to discuss their illness with children. -No correlation poor mental health of adult and psychological disturbance in child. 	<p><u>Rutter’s Child Behavior Questionnaire</u> (caregiver report only, unable to interview children due to lack of privacy)</p> <p>Items translated into Nyanja and other local languages. Used cutoff score of “9” based on studies in London, although studies in Jamaica and Mauritius suggest the cut-off score may need to be lower.</p> <p><u>Short Reporting Questionnaire-20 (WHO)</u></p> <p>Measured psychological health in caregivers, using cutoff score of “7” similar to a 1996 study in Lusaka and studies in Zimbabwe and South Africa.</p>	<p>Not available</p>
<p>Mozambique: Manuel et al (2002)</p>			
<p><u>Assessed 76 orphans and 76 non-orphan controls</u>, and their caregivers in rural Mozambique.</p>	<p>Significant findings orphans vs. non-orphans:</p> <ul style="list-style-type: none"> -higher depression scores (p<.001) -more likely to be bullied (p<.001) -less likely to have a trusted adult or friends (p<.001). <p>Orphan caregivers reported more depression (p<.001) and less social support than controls.</p>	<p>Questionnaire based on Makame et al (2002) – Rand and Beck Inventories</p>	<p>Not available (student author’s supervisor contacted)</p>
<p>South Africa: Wild et al (in press)</p>			

<p>Assessed 204 youth aged 10-19, Xhosa speaking, in urban area of Eastern Cape:</p> <ul style="list-style-type: none"> • 81 AIDS orphans (39F,42M) • 78 orphans other causes (48F,30M) • 43 non-orphans (23F,22M) <p>Assessed demographics and adolescent adjustment (anxiety, depression, self-esteem, externalizing problems). Also assessed psychosocial adjustment and its relation to three protective factors (Barber&Olsen 1997, Olsen&Shagle, 1994, Herman&Dornbusch, 1997):</p> <ul style="list-style-type: none"> • emotional connection • behavioral regulation • psychological autonomy <p>Limitations: 1)Non-random sample; rather recruited AIDS-affected adolescents thru NGOs so may be receiving services or other protective support 2)self-report data so couldn't verify cause of death, and externalizing problems typically under-reported 3)cultural factors</p>	<p>-Depression/anxiety (other orphans>non-orphans, $p<.05$, with AIDS orphans falling between the two groups and not differing significantly from either) -Low self-esteem (other orphans>non and AIDS orphans) -Perceptions of connection, regulation and autonomy in relationship with carer and experiences of connection & regulation in peer and neighborhood contexts significantly associated with better adjustment in orphans ($p<.001$)</p> <p>No group differences in externalizing problems (antisocial behavior)</p>	<p><u>Life Events Questionnaire for Adolescents</u> 21 items <u>Revised Children's Manifest Anxiety Scale</u> yes/no to 28 items and 9 Lie scale items to assess social desirability, check validity of anx score <u>Children's Depression Inventory</u> 10 items, choose 1 of 3 statements, score 0-2 <u>Self-Esteem Questionnaire</u>, 7 items from global self-worth subscale, 4-pt scale <u>Children's Behavior Checklist/Youth Self-Report</u>, response 0-2</p> <p><u>CRPBI</u>, emotional support, 10-item acceptance subscale</p> <p><u>Peer relationship</u> with reference to best friend and bf/gf: 'how much does this person like or love you?' (0-3) <u>Neighborhood connection</u> 4-item scale of time spent with various people (0-6 everyday) <u>Regulation/behavioral control</u>: 5-item monitoring scale (Barber) <u>Peer delinquency</u> 11-item measure, adapted (Elliot et al, 1985, Barber&Olsen, 1997) <u>Neighborhood regulation</u>: 5-item scale of social disorganization <u>Psychological Control Scale-Youth Self-Report</u> (PCS-YSR), 8 items</p>	<p>LEQ: not available</p> <p>RCMAS: alpha 0.8</p> <p>CDI: alpha .64</p> <p>SEQ: alpha .87</p> <p>CBCL/YSR: correlation .66 between 20 Xhosa speaking adolescents and their carer's reports ($p<.001$) in pilot study; alpha for this study .47, deleting items did not improve internal consistency of measure CRPBI: alpha .91</p> <p>Peer questions: the 2 variables significantly correlated $r(37)=-.69$ ($p<.001$)</p> <p>Neighborhood questions: alpha .6</p> <p>Regulation/behavioral control: alpha .69 Peer delinquency: alpha .85</p> <p>Neighborhood regulation: alpha .72 PCS-YSR: alpha .61</p>
--	---	---	---

		describing carers <u>Peer Regulation</u> , 2 items for best friend and bf/gf: ‘how much does this person try to control what you do/think/say?’ (0-3)	Peer autonomy: reported autonomy with best friends and bf/gf was significantly correlated $r(37) = .44$ ($p < .01$)
Kenya: Elmore-Meegan et al (analysis in progress)			
<p>Interviewed <u>956 children</u> (average age 11) and their caregivers in 6 locations, 3 districts (rural and urban) in Kenya with house-to-house coverage.</p> <p>Compared orphans to children living with sick adults to non-orphans (numbers not available).</p> <p>Note: Over half of all children reported being physically punished in school in the last month.</p>	<p>Findings (p-values not given):</p> <ul style="list-style-type: none"> -Orphans significantly more depressed and stressed than non-orphans. -Girls show more anxiety and dysfunction than boys. <p>Other findings:</p> <ul style="list-style-type: none"> -orphans work more than pre-orphans/other children; girls work more hours than boys ---orphans less likely to attend school but scored as well as other children in school -orphans more malnourished (orphans attending school less malnourished) -67 (%) of orphans live apart from siblings 	<p><u>Achenbach Child Behavior Checklist</u> Structured questionnaire adapting the CBCL, the Lansky Ply Scale and Children’s Interview for Psychiatric Symptoms (ChiPS)*</p> <p>Description: Multi-centre validation study of adapted CBCL for OVC in Kenya, “to establish a sensitive scale for measuring behavior in OVC.”</p> <p>Caregivers and children interviewed</p>	<p>Not available. Authors contacted – reply from Dr. Mike Meegan: “The modified Achenbach proved to be a complex instrument for operational programmes. We are currently using a simpler scale that we developed with the Royal College of surgeons. In another study with the Inst of Child health we are using other instruments to compare rural and urban populations.”</p>
Zimbabwe: Nyamukapa et al (2006)			
<p>Factor analysis applied to <u>5,321 children aged 12-17 years</u> interviewed in a cross-sectional national survey in Zimbabwe in 2004.</p> <p>Note: Sexual experiences in adolescents: 10.5% of males and 8% of females reported sexual experience. Maternal orphans (AOR, 1.95; 95% CI, 1.34-2.84) and paternal orphans (AOR, 1.29; 95% CI, 1.00-1.67) but not double orphans (P=1.0) were more likely than non-OVCs to have started sex. Being out of school and increased psychosocial disorder associated with early onset of sexual activity. ($p < .005$) More pronounced psychosocial disorder showed an independent association</p>	<p>Significant findings orphans vs. non-orphans:</p> <ul style="list-style-type: none"> -More psychosocial disorders (males: Coeff, 0.13; 95% CI, 0.06-0.20; females: Coeff, 0.20; 95% CI, 0.11-0.29) and more severe ps disorders for both sexes. -Significant differences in gender with greater ps disorders in girls (Coeff, 0.30; 95% CI, 0.21-0.40): but no significant differences according to age. -For boys only, non-orphans also showed evidence of more psychosocial disorders (Coeff, 0.13; 95% CI, 0.01-0.24). -Orphanhood remained associated with psychosocial disorders after controlling 	<p>Newly created scales: <u>Psychosocial disorders scale</u> (16 items) <u>Social connectedness scale</u> (9 items)</p> <p>Psychosocial disorders variables derived from emotional, psychological, physical, behavior and social-connectedness questions purposively selected from the Child Behavior Checklist, Rand Mental Health and Beck Depression Inventories.</p> <p>Limitations: Cross-sectional design made it difficult to draw inferences on direction of</p>	<p>Alpha .76 Alpha .78</p>

<p>with early onset of sexual activity. Reports of forced sex uncommon, but paternal orphans five times more likely than non-OVC to report this.</p>	<p>for differences in more proximate determinants including poverty, sex and age of household head, school enrolment, and support from closest adult and external sources.</p> <p>-All orphans experienced depression, but few significant differences in anxiety or self-esteem between groups.</p> <p><u>Risk Factors for psychosocial disorders:</u> Being resident in urban area (Coeff, 0.16; 95% CI, 0.04-0.28), on a commercial farm (Coeff, 0.46; 95% CI, 0.08-0.84), in poor hh (Coeff, 0.14; 95% CI, 0.04-0.24) or hh that had received external support (Coeff, 0.21; 95% CI, -0.01-0.44), and not being related to the closest caregiver (Coeff, 0.14; 95% CI, 0.03-0.24)</p> <p><u>Protective factors:</u> Being in female-headed household (Coeff, -0.11; 95% CI, -0.19- -0.02) and receiving psychosocial support from closest caregiver (Coeff, -0.05; 95% CI, -0.09- -0.01)</p>	<p>causality. No data collected on potentially important variables such as child labor, child abuse or sibling separation which could have added to explanatory power of statistical model.</p>	
<p>Zimbabwe: Gilborn et al (2006)</p>			
<p>Assessed 1,258 OVC aged 14-20 in Bulawayo area, comparing groups by exposure to various psychosocial support programs. Partners: REPSSI, CRS/STRIVE, Pop Council/Horizons.</p> <p>Formative qualitative research determined local concepts, manifestations, and domains of well-being among youth. This data was used to draft a survey instrument (in the words of youth) with three intervention groups and one comparison group:</p>	<p>Orphans vs. non-orphans:</p> <p>-Higher daily stress and lower perceived social support (p<.05)</p> <p>-More likely to be rejected by family in a time of need, and made to feel unwelcome in foster home</p> <p>-Far more likely to report not having an adult to talk to (p<.05)</p> <p>-More psychosocial distress and less psychosocial well-being (p<.05), significant for six items suggested of depression (*next column) and 2 items of poor psychosocial wellbeing</p>	<p>Newly developed instrument developed from formal qualitative research data and pre-tested.</p> <p>Separate scales used for measuring psychosocial “distress” and “well-being” based on the idea that these concepts are complex and aspects of distress and well-being can co-exist.</p> <p>3-point response scale modified to a bivariate response for regression analysis.</p>	<p>Not available</p> <p>Items analyzed separately for statistical significance of findings on psychosocial distress and well-being.</p>

<p>340 in community PSS programs only 248 attended Masiye Camp only 112 attended Masiye, became leader/counselor 558 controls (no PSS program exposure)</p> <p>Note: All youth reported high levels of exposure to traumatic events and daily life stress. Psychosocial distress was associated with trauma, daily life stress and a lack of social support. Especially vulnerable groups included females, orphans and younger adolescents. Although exposure to trauma and daily stress increased with age, older respondents reported more self-confidence and self-esteem possibly indicating “post-traumatic growth.”</p>	<p>-All females: higher mean trauma and daily stress scores, more psychosocial distress on 10 items (**next column), but more social support (p<.05) -Older respondents: more ps distress (9 of 19 variables studied) with pronounced increases in anxiety, hopelessness and depression. (p<.05), but also more confidence and self-esteem (p value not reported) -PSS exposure: Males in all PSS programs reported more self-confidence (p<.05) but females in community PSS reported more sadness and lingering grief in the form of sadness and anger (p<.05) -Respondents in each intervention group report more psychosocial distress than controls.</p>	<p>Composite index variables (items weighted with input from local experts) created for: trauma, social support, daily stress and possessions.</p> <p>*items endorsed by orphans suggestive of depression: overwhelmed, feeling alone in the world, trouble concentrating, worry/stress, irritability, loss of appetite</p> <p>**psychosocial distress items endorsed by females included irritability, disinterest in life, feeling alone, somatic symptoms and sadness.</p>	
--	--	---	--

*Questionnaire included: bowel movement outside of toilet, concentration, loneliness, confusion, malnutrition, mood, pessimism; gets teased a lot, would rather be alone than with others, nervous/high strung/ or tense, nightmares, too fearful or anxious, feels too guilty, somatic symptoms, effect of emotional ties, talking, sleeps less than most kids, suspicious, trouble sleeping, wets self during the day, wets the bed, worries, fear, stigma, cruelty, bullying, self-harm attempted suicide, violence, worthlessness, inferiority,

Other Surveys of OVC:

Study Description	Findings	Instruments	Validity/Reliability
Zambia: Nampaya-Serpell (1998)			
Structured interviews with caregivers of <u>645 urban orphans and 291 rural orphans aged 0-15</u> in low-income neighborhoods. Note: Factors affecting school drop-out: urban-poorer families; rural-older orphans.	Urban sample: -children separated from siblings showed more emotional disturbance (p=.05). Rural sample: -more adults in caregiving family associated with higher reports of emotional disturbance (p=.001)	Newly created “Emotional Well-being Checklist”	Not available
South Africa: Wild et al. (2005)			
Psychometric Properties of Self-Esteem Questionnaire tested with English, Afrikaans and Xhosa speaking adolescents in Cape Town. <u>Mean age 15.6</u> (youth aged 12-26 in grades 8 and 11)	Not applicable	<u>Self-Esteem Questionnaire</u> Translated into Afrikaans and Xhosa (some difficulty with Xhosa translation) Five domains of self-esteem in young adolescents, six subscales	Internal Consistency 0.67-0.85 Highest for English version, next for Afrikaans (difficulty with sports/athletics subscale) and lowest for Xhosa (difficulty with sports/athletics, body image and global self-esteem subscales) Test-retest reliability .73-.83 for English version only
Rwanda: Thurman et al (2006)			
Baseline data on 692 Rwandan youth aged 13-24 heading households in WV programs in Gikongoro. Longitudinal operations research will compare the initial intervention group with a comparison group to receive the intervention after one year.	Statistically significant findings (p<.05): -Younger youth feel more supported by relatives/caring adult -Older youth report more mistrust and less help from relatives	<u>Social Marginalization Scale</u> , newly developed, 6-items, five-point scale (strongly agree-disagree using pictorials) of felt and enacted stigma, social exclusion. Youth also responded to open-ended question	Alpha .78 Eigenvalues indicate it is unidimensional; all factor loadings had alpha>.6 except for one (alpha .529)

Further analysis of the above-referenced study of Assessing social support in Burundian progress. Baseline findings reported in Horizons report (Brown et al, 2006)	Makes reports of family and general longitudinal and periodic findings between help from urban female mentoring services and comparison group receiving Support and marginalization	Scale of Support they go to in times of need; and Need level developed items with point response scale concerning available support from relatives, Stricken label adult, peers and others in Community developed, 6 items, 4 point scale	Alpha .67 Alpha .77
Democratic Republic of Congo: Makaya et al (2002)			
Examination and interviews by clinical psychologists with 354 orphans.	Of 11% are not significant peer relationships, but reported low estimates of utilization of support services ” -57% “adaptation problems had about three times as many as the stress than	development (focus groups, free lists of psychosocial distress, stressors and support networks). Instrument was reviewed and amended by local technical committee, translated and back-translated and pre-tested.	N/A
Zambia: USAID/Zambia SCOPE et al (2002)			
Assessed 1600 OVC aged 6 and 13 through caregiver surveys. Data collected as part of a larger baseline data of 1014 households (4419 children) for SCOPE program evaluation in four districts in Zambia. (Limited information on Rwandan low)	People who would help in times of need: 64% school-age OVC attending, 74% said relatives, 57% neighbors and 16% had no one to go to with a Problem of Security :	Newly created instrument developed by Population Council, adapted from existing instruments: Two interviewer administered surveys for caregivers:	Not available
Rwandan low Data gathered on sub-sample of 692 youth-headed households (YHH) in Gikongoro district in the study included and data are from 99 households with parent headed children aged 6-15 was analyzed to determine if children (43%) of optimal state and social network status and emotional functioning of parents (57%) children in their care . Areas of interest: sociodemographics, sex of hh head, time of study lack of service data on basic emotional functioning of youth children and the OVC youth caregivers . Youth caregivers reported on children in their care. Note: Half of YHH met cutoff criteria for depression.	-critical poverty for most hh; -XHH report of more depression, social isolation, lack of cash and ¼ supports more likely to be displaced or stopped Psychosocial issues worsened general health first decreased interest in to play Girls 66% report depression than boys (p=.029) -Marginalization and depression highly linked (26% 58%) and see them. 90% of caregivers report w/ adult support that is very responsive in do not report problem like to report younger children has poor health status than children in their district (p=.041)	26-item Psychosocial Issues survey. CES-D adapted for Rwanda 18-item Emotional Wellbeing Checklist (4-point scale). Interviewer administered questionnaire for ages 6-12, 13-18, and Social Marginalization Scale , newly developed (see above) Key psychosocial areas: perceived Available Adult Support newly developed with items: children, scale (agree/disagree) death and family cohesiveness.	Alpha .84 each scale item had factor loadings >.4 except four items retained as they were part of standardized CES-D Alpha .78 Alpha .87 (all items with factor loading >.8)
Zambia: Volle et al (2002)			

Interview of 788 adolescent orphans randomly selected from 4 districts in Zambia	89% of orphans were “always or sometimes unhappy” and 18.6% had run away from their new homes	Non-standardized (newly created) survey instrument administered by psychosocial support workers	Not available
Zimbabwe: Rusakaniko et al (2006)			
<p>Assessed <u>OVC age 6-14 (n=761) and 15-18 (n=447) and their guardians (n=1471)</u>. Cross-sectional study to obtain baseline data on OVC and their caregivers in randomly selected wards of two districts in Zimbabwe (C-Chimanimani and B-Bulilimamangwe). -household living situation and relationships -emotional well-being -experiences of stigma and discrimination Sampling frame derived from 2003 BRTI/NIHR OVC Census Data to identify households with vulnerable children.</p>	<p><u>6-14 year olds</u>: 5% in C reported having engaged in sexual intercourse or being inappropriately touched on private parts; 10% in B report scary dreams/ nightmares and 9% report trouble falling asleep.</p> <p><u>15-18 year olds</u>: 50% (C) and 60% (B) still bothered by parent(s)’ death;</p>	<p><u>Vulnerability assessment/ indicator score from Census Data</u>: summary of hh situation in terms of food & clothing availability and care for children in hh.</p> <p>Questionnaires adapted from OVC generic protocol compiled by HSRC comprising <u>3 sets of OVC PSS baseline questionnaires developed by SCOPE and FHI</u> adapted to Zimbabwe culture/context. Measures assessed: food intake, psychosocial issues, risk-taking, decision-making processes and emotional well-being.</p>	Not available

Psychosocial Surveys of Adolescents Exposed to Violence/War

Study Description	Findings	Instrument	Validity/Reliability
North Uganda: Bolton et al (2006)			
<p>Assessed <u>667 adolescents</u> Assess nature and extent of impact of conflict on adolescents to determine appropriate intervention; impact of interpersonal group therapy.</p> <p>Qualitative data from children/adults in camps:</p> <ol style="list-style-type: none"> 1) Social relations marked by aggression, sexual misconduct in boys and girls, rape, stealing, fighting, alcohol abuse 2) Lack of parental guidance and support...no warmth between children and parents 3) Depression/anxiety-like symptoms leading to hopelessness 4) Overall, adolescents and caretakers prioritized mental health effects of crowding into camps over the direct impacts of abduction, violence, and threats of violence. 	<p>Using assessment tool (APAI, adapted SDQ, functional impairment scale and demographics), <u>339 (of 667) adolescents</u> found to have 'problems' appropriate for IPT, 6 were actively suicidal (received IPT and referral for crisis intervention).</p> <p>Post-IPT assessment: statistically significant improvement in symptoms on 4 of 5 measures (3 of depression-like problems, 1 of anxiety, 1 of conduct) compared to control and creative-play group.</p>	<p>Questionnaire in Luo, APAI (Acholi Psychosocial Assessment Instrument), was newly created based on qualitative study results and validated. Validation study conducted with 178 adolescents aged 14-17.</p> <p>APAI contains depression-like symptoms scale: 52 signs and symptoms associated with 5 locally derived mental health and psychosocial problems plus 8 pro-social activities identified in qualitative study. <i>[35 items including items for 3 local syndromes]</i></p> <p>APAI compared with Western conceptions using the SDQ.</p>	<p>Alpha .91 for APAI scale. Alphas .83-.84 for the three separate subscales specific to local syndromes.</p> <p>Adequate and significant correlation between the total APAI and the SDQ, and the APAI locally derived subscales and the SDQ emotional problems subscale ($r=.59, .61, .62$)</p> <p>Adequate inter-rater reliability ($r=.74$. and test-retest reliability ($r=.84, .85$) for total APAI and total depression symptoms scales, respectively.</p> <p>In sum, "the...APAI...has good psychometric properties and is able to distinguish locally defined cases...from non-cases."</p>
South Africa: Ward et al (in submission)			
<p>Assessed <u>377 young adolescents</u> average age <u>11.6 years</u> (age range 11-15).</p> <p>Assess the extent to which children's individual, family, school and peer group characteristics influence resilient responses to violence exposure in grade 6 students in high violence community in Cape Town (majority coloured population).</p>	<p><u>Positive associations:</u></p> <ul style="list-style-type: none"> -witnessing/victimization of violence and depression ($p<.01$) -witnessing violence and anxiety ($p<.05$) -victimization and anxiety ($p<.01$) -victimization and conduct problems ($p<.01$) -peer delinquency and depression ($p<.05$), conduct problems ($p<.01$) <p><u>Negative associations:</u></p>	<p>SAHA scale items:</p> <p><u>Conduct Problems</u> (3 subscales conduct problems, less severe delinquency and severe antisocial behavior, 16 items)</p> <p><u>Conventional Involvement</u> (group spare time and individual activities subscales, 5 items)</p> <p><u>School Support</u> (5 school</p>	<p>Alpha .89</p> <p>Alpha .72</p> <p>Alpha .69</p>

	<p>-involvement in conventional after-school activities and anxiety (p<.01)</p> <p>-school support and depression, conduct problems (p<.01)</p> <p><u>No association:</u></p> <p>-parent support and any resilience domains, contrary to the literature; however, <u>participants reported they were most likely to be victimized in their homes</u></p>	<p>environment and academic motivation subscales, 8 items)</p> <p><u>Peer Delinquency</u> (8 items)</p> <p><u>Parent Support</u> (four subscales of parental supervision, warmth, involvement and inconsistent parenting, 6 items)</p> <p><u>Future Expectations</u> (5 items)</p> <p><u>Perceived Competence Scale for Children</u> (7 items)</p> <p>-competence assessed across cognitive, physical and social domains, and self-worth subscale; binary response scale: “‘sort of – really’ true for me”</p> <p><u>BASC anxiety</u> (12 items) and <u>depression</u> (12 items) subscales</p> <p><u>Substance Abuse</u> (4 yes/no questions)</p> <p>Exposure to Comm Violence</p>	<p>Alpha .84</p> <p>Alpha .77</p> <p>Alpha .81</p> <p>Alpha .64</p> <p>Alpha .81</p> <p>Alpha .52</p> <p>N/A</p>
--	--	---	--

Qualitative and Descriptive Studies:

Study Description	Findings	Methods
Zimbabwe rural: Foster et al (1997)		
Qualitative study to ID issues of concern to affected children, families and community members. Topics: extended family support, stigma & discrimination, psychological problems.	Children reported anxiety, fear, stigmatization from friends and community, exploitation, problems at school, and depression and stress.	Focus groups and interviews with <u>40 orphans, 25 caretakers and 33 other community members</u> near Mutare, areas receiving FOCUS program
Zimbabwe: Foster et al (1995)		
Assess orphan prevalence in rural community and explore community's coping mechanisms for orphan care. <u>"orphan" = child<14, mom and/or dad has died</u> Note: Recent increases in parental deaths were noted; 50% of parental deaths since 1987 could be ascribed to AIDS.	18.3% (95% CI 15.1-21.5%) of households included orphans. 12.8% (95% CI 11.2-14.3%) of children under 15 years old had a father or mother who had died; 5% of orphans had lost both parents. Orphan prevalence highest in a peri-urban rural area (17.2%) and lowest in a middle income medium density urban suburb (4.3%).	Orphan enumeration survey with 570 hh in/around Mutare. (Sample: 60 clusters of 10 hh randomly selected with sampling weighted to reflect population data.) Re-interview orphan hh for estimates of AIDS-related deaths and relationship of caregiver to orphan; Focus Groups with 12 groups of community members, caregivers, teachers: <ul style="list-style-type: none"> • Coping behaviors: families, orphans, community • Discrimination, exploitation, stigma • Potential for community-based initiatives
Uganda: Ntozi & Mukiza-Gapere (1995)		
Care of orphans, societal coping with orphan problem. Note: NGOs have set up local orphanages to care for orphans.	-Surviving fathers, mothers and relatives often sick with AIDS and too weak to care for child; or too young or old to care for child. -Surviving widows stigmatized by husband's family (i.e. widow not inherited, widow considered witch who killed husband, family abuse by stealing land and resources, etc) affecting orphan care. -Large numbers of orphans overwhelm relative caregivers.	Focus groups (12 female – 104 participants, 12 male – 128 participants) aged 35-92. Focus groups (11 female – 144, 11 male – 113 youth) aged 14-34

	-Orphans stigmatized by foster families because of presumed HIV+ status. -Land shortage leading to food shortage.	
Kenya: Nyambedha et al (2001)		
Describe orphan support systems in western Kenya. Assessed: SES; orphan demographics; views, opinions, knowledge, attitudes toward orphan situation; how cultural and societal institutions support orphans and how orphans adapt	High inability of orphan households to afford school fees. Lack of food, medicine and clothing also prevalent. Limited resources within the traditional, kinship-based support systems. Limited contribution from area community-based groups. Exponential increase in orphan prevalence.	Purposive sampling of 100 orphan caretakers In-depth interviews 20 hh. 24 key informant interviews 14 focus groups: women in 40's with poor SES, men in 50's, orphans age 10-14. Narratives and longitudinal hh monitoring for 6 months with 5 orphans
Zimbabwe: Walker (2002)		
Survey of needs of children in CHH and available support. Interviewed <u>17 CHH</u> living on commercial farms and other children (<u>46 children < age 18, 1 age 20</u>) Interviewed 27 community members: 10 farm health workers, 11 general members, 4 teachers, 2 farmers	*unable to retrieve findings*	<u>Child interviews:</u> -Material and basic needs -Level of emotional support/guidance available -Future expectations -Abuse and exploitation <u>Community interviews:</u> -Perceptions of CHH, support available to CHH

Appendix B: Focus Group Findings

With the assistance of REPSSI staff, focus groups were conducted in Zimbabwe and South Africa to test drafts of the caregiver and youth instruments in June 2006. Findings from those focus groups have informed instrument development in terms of priority areas of need and linguistic modifications. Findings are presented briefly, and the focus group guide and draft caregiver and youth instruments used in focus groups follow.

Focus Group Cape Town, South Africa

A focus group with 16 girls, aged 13-17, was led by Jonathan Morgan in Masiphumelele Township in the South Peninsula of Cape Town on June 22, 2006. The venue was the Ncedanani programme (a social assistance programme for orphans affected by HIV/AIDS) and the girls were participants in the program. Unfortunately no boys were present. Due to logistical constraints, time for the focus group was limited which did not allow for in depth exploration of responses/attitudes to the survey. Zonke Maseko, the social worker responsible for the group, provided translation. Assistance (ensuring that informed consent was obtained from participants and caregivers) was also provided by Thembisa Ngcayasha who is the administrative officer for Ncedanani.

Participants completed the instrument with assurances that there were no wrong or right answers, that all responses were confidential and that for the purposes of this exercise, we were interested in their opinion of the questions, rather than their personal answers.

General reflections of the group on the items indicated they thought the questions were good and captured issues important to youth in difficult circumstances and serious risks:

“They are good questions, we are facing things in other ways that the question asks.”

“They are good questions because they help us to know ourselves and think about our future.”

“Even at home, we think about these things. (prompt: which things?) The things you ask in question 9a.”

The group was unable to articulate anything the survey left out that might be important, how well the survey captured the feelings and behavior of youth when they are all right or troubled, or suggestions for additions or deletions. They reported the questions made sense in their language.

Facilitator’s note: there was a sense that the questions were “downers” and some positive items might be helpful.

Q: How well do you think other youth in Africa will understand the questions?

“They will understand it well.” “Some will not, it depends on where they are.

(prompt: can you say more about that?) Maybe it has to do with how rich or poor they are.”

Q: Which specific items are confusing or hard to understand?

Items 2a) “exclude”; 3Bb) “open communication”, 3Bd) “necessities” (requires examples).

Facilitator’s comments: “exclude” was difficult in terms of translation and they may be more familiar with a word like “discriminate.” “Open communication” was difficult both culturally and in translation, and requires examples to clarify. “Needs” would be more easily understood than “necessities.”

Q: Which questions could potentially be upsetting to youth? Do you think we should not ask these questions...why or why not? How would you rephrase the questions so they are not so upsetting?

“I found 9B questions upsetting but they are important”

“I found the questions 9B, no one really loves me upsetting to think about.”

(prompt: should we leave these questions out? – respondent couldn’t answer)

“I found the questions about killing myself upsetting because we do think of these things. (prompt: do you think they should leave these questions out?)” No, they are important.”

Q: Are there any questions hard to answer or understand?

There was a rich discussion in which it was expressed that the questions might be not so good in that even though confidentiality was promised, this might not be trusted, and there were many questions that were difficult to answer honestly.

“For example item 8a), we sometimes do these things (drink alcohol) when we are very troubled, or just for fun, or to forget, but if we answer yes, even if we say less often, we might be misunderstood or get into trouble.”

Facilitator’s note: they might be misunderstood to be alcoholics when it is just occasional use of alcohol.

“To say we stay out of school, especially when our caregiver makes us do this, it’s hard to be honest about this, we might get into trouble.”

Regarding item 9B “I look OK...I am ugly,” the group unanimously felt this was an upsetting line of enquiry and a set of questions that should not be asked.

In terms of preferences for options given for questions 3 and 9, not all participants indicated a preference, but those that did stated the following reasons for preferring one question over another:

Preferences for 9B (7 respondents):

“It’s all about being you, telling it as it is, not just yes or no.”

“Because it is about our feelings.”

“It is a right question to ask how youth feel about their futures in order to make life easier.”

“It can teach youth to be open in their lives.”

“Teaches us many things about life.”

“It helps us to know our rights and responsibilities.”

Preferences for 9A (3 respondents):

“Because it tells youth how to cope and have to be strong in everything.”

“Because there are children doing bad things.”

Preferences for 3A (8 respondents):

“I prefer 3A because it shows where you get help like clinics and social service agencies.”

“Because they feel alone sometimes and think of killing themselves.”

“Because there are other things we cannot talk about.”

“It is the life we live and they can be open in their lives.”

Preferences for 3B (3 respondents):

“It helps to understand where we are.”

Focus Group Bulawayo, Zimbabwe

Focus group discussions were held across two days: a day with youth and a second day with caregivers at the Masiye Camp just outside Bulawayo, Zimbabwe. The following report was prepared by facilitator Doreen Muza of REPSSI, with input from Brighton Gwezera.

Youth Focus Group

The youth group comprised 11 boys and 8 girls who were attending a camp at Masiye Camp. The youths were largely from urban Bulawayo whose ages ranged between 17 and 22.

	Sex	Age
1	Male	22
2	Female	17
3	Female	17
4	Female	18
5	Female	18
6	Female	20
7	Female	22
8	Female	22
9	Female	26
10	Male	17
11	Male	18
12	Male	18
13	Male	19
14	Male	19
15	Male	19
16	Male	20
17	Male	20
18	Male	20
19	Male	21

To start with, participants were walked through the consent form which they were asked to sign depending on whether they wanted to participate in the plenary discussion. After signing the consent forms, the youths went through the survey instrument and answered the questions individually. It took a maximum of twenty-five minutes for

everyone to be done filling in the questionnaire though six of them managed to complete it in the initially allowed time frame of ten minutes. The group discussion took up to forty five minutes.

The following issues were raised during the group discussion:

- a) Generally the group found the questionnaire to be simple and straightforward to answer and some of the words they used to describe it are: interesting, straightforward, easy. Four members found it quite difficult and confusing though largely due to the complexity to them of some of the words that were used to design the survey: mainly two words, necessities (“needs” was preferred) and carers (“guardians was preferred”).
- b) Question 9B was said to be a better question as it specified feelings and emotions and made one look closely into what kind of person they are
- c) Question 4 needs to be reworded for it to accommodate children who are heading households
 - the youths also referred to the survey as a whole as one that didn’t really direct questions to youth who were heading households and that such questions should be added
- d) Group members also suggested that for questions such as 3B and 9B a field where they can write their own responses be added because sometimes the scaling doesn’t accurately reflect the truth of their opinions
- e) The group felt that question 3B was difficult the answer because the scaling was a too close. For example in vernacular “hardly ever” and “not at all” have more or less the same meaning. Youths also mentioned that the implications of saying hardly ever could be negative and yet one would know that their guardians hardly ever give them money because they don’t have the money though they would really want to give them the money. This they said could be bettered by including an “other” field where they could give an explanation or state their exact opinions. However they thought 3B was better than 3A because the questions are unpacked and a broader answering option is given.
- f) In question 9B, the statement about being satisfied with one’s looks or hating oneself wasn’t really well received. They said it was a negative question and should be removed.
- g) Answering questions two evokes some unpleasant emotions though it’s a necessary questions to ask
- h) A recommendation was also made for inclusion of questions that enquire about the treatment of children by their respective guardians, such as specific questions to ask if they felt they were treated well by their respective guardians, including whether or not the are fed sufficiently, receive adequate clothing, etc.
- i) Another question they thought was important to include was a question directed towards the youths to find out what they are doing in life and if they aren’t doing anything the reasons why because some of the reasons might be an indication of a problem: from female respondent: “What are you doing with your life at the moment and if nothing why?”
- j) 12 of the members felt the questionnaire was best presented in English rather than vernacular; although they did not specifically state that the questions would be a

- problem in the vernacular, only that the questions were well-presented in English (they were not translated).
- k) Generally the group thought the questions were very relevant to African youths and pertained to issues that affected them at one time or another.
 - l) However the wording in some questions need to be changed to simple English e.g. carers – guardians ; Necessities – needs, and in this case it would be better to provide examples of what these necessities could be or to list them and the respondents can tick what they do or don't have.
 - m) Lastly, some suggested questions to be included to address CHH were:
 - how much responsibility they had e.g. how many siblings or dependents to take care of
 - source of livelihood of any
 - age and sex
 - why they ended up being CHH, e.g. in African tradition when children lose their parents there is usually extended family to assume responsibility for them (though its not happening as much now) so this question would be important to ask because some of these children could have been abandoned by relatives

Caregiver Focus Group

This was a group of four patrons from Youth for a Child in Christ (YOCIC). YOCIC works with children in the communities through kids clubs. Each kids club has a leader who is a young person from the community. The kids club then identifies an adult within the same community who plays the role of patron to them and helps them with counseling and taking up other issues that the youths might not be able to handle on their own.

The following issues were raised during the group discussion:

- a) the patrons were quick to point out that the language was difficult and complex for them and the survey would be better in vernacular as that way it would be easier for them to understand the questions and as well provide suitable responses. *Facilitator notes that the instrument was translated verbally, and what they meant was they would like to receive the hard copy written in vernacular.*
- b) the questions were relevant and addressed issues that were a true reflection of what was happening in the lives of children in Africa
- c) 4B was said to be a better question because it was more explicit and had a broad scaling that allowed them to think about the questions more. It also gives specific responses which makes the question easier to answer
- d) Question 5 needs to be reworded to accommodate children infected with HIV/AIDS the question asks about the community's attitude towards children whose parents have HIV and AIDS, they felt it was important to ask a question that brings out the community's attitude towards children who are infected as well
- e) In addition to the "disciplining methods" lined up in question 4b, the patrons felt it was important to add on a few more methods that are frequently used as disciplining measures in the community: - denying the children food; sending the children out into the cold and night; stopping them from going to school;

overworking the children or giving them more chores than normal; denying children their inheritance, etc.

- f) In addition to the responses also given in question 6, the patrons felt it was also important to add stealing as one other worrying behaviour youths could actively engage in.

Facilitator's comments and reflections:

Questions 1 and 2 might not be relevant to caregivers in Africa as first instinct in such situations would not be to seek medical care but rather to talk to the child and try to establish the reasons behind such behaviour and then take it from there. Likewise if a caregiver was to have such a problem they would initially find someone to talk to, a friend or church mate, or they would pray about it rather than go to the clinic or seek medical attention when I first saw this question it seemed really irrelevant in terms of the African practice. Being emotionally unwell (eg, depression, feeling low being miserable etc) are not considered medical illnesses especially by the lower class population. They felt if the question really had to be there maybe it would ask who they turn to when they feel sad or how often they feel sad, otherwise they thought it should be taken out. I don't know if you are asking the question to find out how much they prioritise emotional wellbeing by seeking medical attention or other for it or if you want to find out how often they feel this way. If it's the former, I think the question can be modified slightly by adding friend, pastor, etc instead of spiritual or traditional leader. If it's the latter then rewording it as suggested by the patrons would be ideal with a scaling option (eg, often, hardly, ever, not at all).

Focus Group Guide

Purpose of the Focus Group:

To gather the opinions of young people who are orphaned or vulnerable on an instrument designed for youth in Africa. The instrument is a draft set of questions that will be used by UNICEF to measure the psychosocial well-being of youth in many African countries. It will be conducted as a national-level household survey, and is part of a larger document of measures for the well-being of orphaned and vulnerable children. The other measures ask questions about education, malnutrition, sex before age 15 and so on. The questions in this instrument represent a “psychosocial vulnerability and resilience” measure, and complement a separate measure about the connection of youth to a primary caregiver.

The questions in the instrument intend to capture the risks and resources that youth have in their households, communities and within themselves that make a difference to their psychological and social health and functioning. Things we would like to know:

- Did we capture the things that trouble youth? Did we leave anything out?
- Do the questions make sense to young people in their own language?
- Are these things important in the lives of youth? Are there some things that are not so important and that we should take out?
- Are any of the questions hard to answer or understand?
- Are any of the questions upsetting?
- And...in their opinion...should we use these questions to ask other youth in Africa about their feelings and experiences?

Setting up the Focus Group:

Ideally, a focus group is conducted with one person to lead and another person to record the discussion (by tape recorder or by taking notes by hand). For this focus group, we would like to talk with youth aged 12-17, with a fairly equal mixture of boys and girls. Ideally, you should have a minimum of 10 and maximum of 15 participants. Things you will need for a successful focus group are:

- **Consent forms understood and signed by youth and their caregiver.** Some young people live on their own and are considered “emancipated.” These young people can sign for themselves if there is no caregiver. Please read the consent form in the local language to children and their caregivers. Ask if there are any questions. If the youth and the caregiver agree, then have them sign the forms.
- **A private, comfortable and quiet space.** Chairs should be arranged in a circle. The space should be private (so other people are not listening in, or walking in and out of the room disturbing the group), comfortable and private.
- **An introduction to explain the roles of the facilitator and recorder, and the purpose and format of the group:**
 - Explain what the participants can expect

- How long the group will be (about 1 to 1 ½ hours)
- What the group will do (talk and gather opinions and ideas)
- What the group will not do (it is not therapy and it is not a test)
- **Establish ground rules for the discussion:**
 - Respect what others have to say...don't criticize. Everyone's ideas are important.
 - One person talks at a time...no interrupting.
 - Keep confidentiality...what is said in this room stays in this room.
 - Ask if the group would like to set any other ground rules.

Tips for the facilitator: The goal of the focus group is to gather as much information as possible from the participants about this topic. The following tips may be helpful to you:

- Use open-ended questions to stimulate discussion rather than yes/no questions which do not give you specific or nuanced information.
- Some participants may be very vocal while others may be very quiet. Try to hear from all participants, including both boys and girls and young and older youth in the group. Gently encourage more quiet participants to engage in the discussion to get their viewpoint. Do not allow for side conversations – all discussion should be together with the group.
- The youth are the experts in this discussion, and there are no right and wrong answers. Do not correct or make any judgment (bad or good) on what the participants say. Do NOT offer your opinion. Acknowledge and respect all contributions to the discussion.
- Use the guide questions below in a flexible way. Try to cover each question, but do so naturally with the flow of the discussion. The questions do not have to be covered in a specific order, and you may find that the participants spontaneously begin to talk about a certain topic.
- Be natural and conversational. Listen actively, respond and probe for more information. This will help young people to know their opinions are important and you want to hear them.
- Use probing statements to get more information, for example...”Tell me more about that.”

Focus Group Questions

The following questions will be used to frame the focus group. They do not have to be asked in order. If youth spontaneously bring up the topic in the question, then go with their discussion. The group may talk about a related issue, and you can use your judgment to continue for a time on that topic (if it is relevant to the goal of the group), or to redirect the group in the interest of time back to the task at hand. Please be sure to cover all of the questions in the time frame allotted for the group. Out of respect for the participants, do not go over the time limit! The recorder can help the facilitator to keep time and stay on schedule. You can go back if there is time at the end to clarify any points.

A sample of the instrument has been provided and may be useful for leading off discussion. You may want to start by handing out the instrument and explaining what it is for: “to understand what troubles youth in their lives at home and in their community, and within themselves.” You can have the participants fill out the instrument, but make sure they do not put their names on the paper to ensure confidentiality. Please record how much time it takes for the youth to fill out the instrument, but allot no more than ten minutes so that you have plenty of time for discussion.

The purpose in filling out the instrument would be for them to see the questions, and reflect upon them together as a group. Please note there are two questions in the instrument that have an alternative question. We would like the opinion of the youth on which question they think is better. There is space on the paper for them to write their opinion.

The following are the main questions, and probing questions do stimulate and guide the discussion.

Questions for Youth:

All first read the instrument. “Tell me what you think of the instrument.” First allow open-ended discussion, then probe:

1. How well did the instrument capture the things that are important to young people in very difficult circumstances?
2. How well did the instrument capture the serious risks to youth in their lives?
3. What things did the instrument leave out that you think are important?
4. How well did the instrument capture the feelings and behavior of youth when they are troubled or when they are doing all right?
5. What would you suggest we take out or add to the instrument to better capture these things?
6. How well do you think youth in Africa will understand these questions?
7. Which specific items confusing or hard to understand?
 - a. How would you rephrase them?
8. Do the questions make sense to young people in their own language?
9. Which questions could potentially be upsetting to youth?
 - a. Do you think we should not ask these questions...why or why not?
 - b. How would you rephrase the questions so they are not so upsetting?
10. Overall, give your opinion of this set of questions in capturing the key issues affecting young people in difficult circumstances.

Questions for Caregivers:

All first read the instrument. “Tell me what you think of the instrument.” First allow open-ended discussion, then probe:

11. How well did the instrument capture the things that are important to caregivers raising young people in very difficult circumstances?
12. How well did the instrument capture the serious risks to youth in their lives?
13. What things did the instrument leave out that you think are important?
14. How well did the instrument capture the things that caregivers most worry about for the well-being of youth in their care?
15. What would you suggest we take out or add to the instrument to better capture these things?
16. How well do you think other caregivers in Africa will understand these questions?
17. Which specific items confusing or hard to understand?
 - a. How would you rephrase them?
18. Do the questions make sense to you in your own language?
19. Which questions could potentially be upsetting to caregivers?
 - a. Do you think we should not ask these questions...why or why not?
 - b. How would you rephrase the questions so they are not so upsetting?
20. Overall, give your opinion of this set of questions in capturing the key issues for caregivers raising young people in difficult circumstances.

Thank all respondents for their participation and offer refreshments!

Caregiver Instrument for Focus Group Discussion

This is a survey for the people like yourself who care for children in difficult circumstances in Africa. Some of you are parents, grandmothers or grandfathers, aunts and uncles, or others who children depend on for support and guidance. We are showing you this survey to get your opinion about it. You are our experts in understanding the challenges caregivers may be facing as they try to provide a good environment for children to grow, be healthy and be happy. We would especially like your opinion about these questions. Do they make sense? Are they easy to understand? Do they capture the important things that may be risks to your own well-being or the well-being of the children in your care? Are any of the questions upsetting or hard to answer? Do you think we should ask these questions of other caregivers in Africa? Did we leave out anything important?

As you read through this survey, you can try answering the questions to see how it goes. Then you will talk together as a group with the leader about this survey and give your ideas.

THANK YOU FOR HELPING US MAKE A GOOD SURVEY FOR PEOPLE WHO CARE FOR CHILDREN AND YOUTH!

1. Have you felt you needed to take your child to a health worker (clinic nurse or doctor, spiritual or traditional healer) because they are spiritually or emotionally troubled (sad, having problems with nerves, being much more disobedient than usual)?

YES or NO

2. Have you felt YOU needed to go to a health worker (clinic nurse or doctor, spiritual or traditional healer) because you were spiritually or emotionally troubled (sad, having problems with nerves)?

YES or NO

3. Over the past year, has anyone in the household kicked, bitten, slapped, hit with a fist, threatened with a weapon (knife, stick or gun) or thrown something at another adult who lives here?

YES or NO

a) If yes, how often does this happen?

Weekly Monthly Less Often Never

Below are two different questions (4A and 4B) that ask caregivers about how they discipline their child. Please look at both questions carefully. Which question do you think is better to ask caregivers in Africa? Please tell us your opinion below...

4 A) How often do you or another adult in the household...

a) Use a stick, belt, hairbrush or other hard

item to discipline your child? Weekly Monthly Less Often Never

b) Slap, punch or hit your child
on his/her head or face? Weekly Monthly Less Often Never

4 B) All adults use certain methods to teach children the right behavior or to address a behavior problem. I will read various methods that might be used and I want you to tell me how often you or anyone else in the household who is responsible for children (your husband, partner, mother, etc) have used this with any of the children in the last year: never, once or twice, three to five times, six to ten times, or more than ten times in the last year. If you have not done this in the past year but have done this previously, please indicate this.

a) Hit him or her on the buttocks with an object such as a stick, broom, cane, or belt

	<i>Once or twice</i>	<i>3-5 times</i>	<i>6-10 times</i>	<i>> 10 times</i>	<i>Not in past year</i>	<i>Never</i>	<i>N/A</i>
Responding parent/adult or other carer in household	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

b) Hit elsewhere (not buttocks) with an object such as a stick, broom, cane, or belt

	<i>Once or twice</i>	<i>3-5 times</i>	<i>6-10 times</i>	<i>> 10 times</i>	<i>Not in past year</i>	<i>Never</i>	<i>N/A</i>
Responding parent/adult or other carer in household	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

c) Hit him/her on head with knuckle or back of the hand

	<i>Once or twice</i>	<i>3-5 times</i>	<i>6-10 times</i>	<i>> 10 times</i>	<i>Not in past year</i>	<i>Never</i>	<i>N/A</i>
Responding parent/adult or other carer in household	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

d) Threatened to invoke ghosts or evil spirits, or harmful people

	<i>Once or twice</i>	<i>3-5 times</i>	<i>6-10 times</i>	<i>> 10 times</i>	<i>Not in past year</i>	<i>Never</i>	<i>N/A</i>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Responding parent/adult or other carer in household

e) Kicked him/her with a foot

	<i>Once or twice</i>	<i>3-5 times</i>	<i>6-10 times</i>	<i>> 10 times</i>	<i>Not in past year</i>	<i>Never</i>	<i>N/A</i>
Responding parent/adult or other carer in household	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

f) Hit him or her over and over again with object or fist (“beat-up”)

	<i>Once or twice</i>	<i>3-5 times</i>	<i>6-10 times</i>	<i>> 10 times</i>	<i>Not in past year</i>	<i>Never</i>	<i>N/A</i>
Responding parent/adult or other carer in household	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

g) Threatened him/her with a knife or gun

	<i>Once or twice</i>	<i>3-5 times</i>	<i>6-10 times</i>	<i>> 10 times</i>	<i>Not in past year</i>	<i>Never</i>	<i>N/A</i>
Responding parent/adult or other carer in household	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MY OPINION: I thought question _____ (select either 4A or 4B) was better to ask caregivers because....

5. How does this community feel about children whose parents have HIV/AIDS?

a) Adults in this community are generally concerned for these children. YES or NO

b) The community excludes these children. YES or NO

c) These children are more likely to be hurt (abused or taken advantage of) than helped

- | | | | |
|--|-----|----|----|
| by people in this community. | YES | or | NO |
| d) The community feels these children carry with them the bad deeds of their parents. | YES | or | NO |
| e) People in this community want to help these children, but they have too many problems of their own. | YES | or | NO |
| f) The community feels these children cause problems in the neighborhood/village. | YES | or | NO |
| g) People in this community make fun of or talk bad about these children. | YES | or | NO |
6. Are you concerned that your child...
- | | | | |
|---|-----|----|----|
| a) Will get into trouble with the law? | YES | or | NO |
| b) Is violent? | YES | or | NO |
| c) Takes alcohol or drugs? | YES | or | NO |
| d) Is deeply unhappy? | YES | or | NO |
| e) Often truants from school when he/she should be there? | YES | or | NO |
| f) Is having sex? | YES | or | NO |

The End...Thank You!

Youth Instrument for Focus Group Discussion

This is a survey for young people like yourself living in different places in Africa. We are showing you this survey to get your opinion about it. You are our experts in understanding youth, the difficulties in their lives and how they feel about those things. We would especially like your opinion on these questions, for example: Do they make sense? Are they about important things in the lives of youth? Are they hard to answer? Are they upsetting? Do you think we should use these questions to ask other youth in Africa about their experiences and feelings? We are trying to understand the things that trouble youth in their families and in themselves – did we leave out anything important? As you read through this survey, you can try answering the questions to see how it goes. Then you will talk together as a group with the leader about this survey and give your ideas.

THANK YOU FOR HELPING US MAKE A
GOOD SURVEY FOR YOUNG PEOPLE!

Please circle your answer...

1. Have you felt you needed to consult a health worker (clinic nurse or doctor, spiritual or traditional healer) because you were spiritually or emotionally troubled? YES or NO

2. Do you feel...
 - a) People in this community exclude children whose parents have AIDS? YES or NO
 - b) No one cares about you in this community? YES or NO
 - c) You are isolated from others in this community? YES or NO
 - d) People make fun of your situation? YES or NO

Below are two different questions (3A and 3B) that ask children about their relationship with close people in their life. Please look at both questions carefully. Which question do you think is better to ask youth? Please tell us your opinion below...

- 3 A)** Do you have someone in your life you can depend on...
 - a) For advice and guidance? YES or NO
 - b) To go with you to the clinic, schools or social service agency if you needed help? YES or NO

c) To comfort you when you feel sad or sick? YES or NO

3 B) Think of someone in your life that you depend on. How often does that person...

a) Comfort me? Hardly ever Not at all Sometimes Often Very often

b) Have open communication with me? Hardly ever Not at all Sometimes Often Very often

c) Trust me? Hardly ever Not at all Sometimes Often Very often

d) Provide for my necessities? Hardly ever Not at all Sometimes Often Very often

e) Give me money? Hardly ever Not at all Sometimes Often Very often

f) Buy me things? Hardly ever Not at all Sometimes Often Very often

MY OPINION: I thought question _____ (select either 3A or 3B) was better to ask youth because....

4. How often do adults in your home...

a) Shout at each other? Weekly Monthly Less Often Never

b) Hit each other? Weekly Monthly Less Often Never

5. How often do your carers...

a) Use a stick, belt, hairbrush or other hard item to discipline you? Weekly Monthly Less Often Never

b) Slap, punch or hit you on your head or face? Weekly Monthly Less Often Never

6. How often have you...

a) Been attacked outside your home? Weekly Monthly Less Often Never

b) Seen someone stabbed, beaten or shot outside your home? Weekly Monthly Less Often Never

7. Do you ever have to stay out of school to attend to household duties (for example, fetching water/ wood, tending animals, working on the land, caring for younger children or sick adults, or getting money to support the household, etc?

YES or NO

If yes,

how often does this happen? Weekly Monthly Less Often Never

8. During the past year, how many times (if any) have you...

a) Been drunk or very high from using alcoholic beverages or drugs (marijuana, daka, etc)? 0 1 2 3-4 5+

b) Been arrested by the police for your behavior? 0 1 2 3-4 5+

c) Threatened someone seriously or beaten up somebody? 0 1 2 3-4 5+

Below are two different questions that ask children about their feelings. Please look at both questions carefully. Which question do you think is better to ask youth? Please tell us your opinion below...

9 A) In your current situation, do you feel that...

a) things are so bad, I have lost hope for the future YES or NO

b) things are so bad, I don't want to live anymore YES or NO

c) I will never get married, have children or get a job YES or NO

d) I can cope with life's ups and downs YES or NO

9 B) These questions look at sadness and other difficulties which many people experience at some point in their lives. The questions are arranged in groups of 3 statements. Please read each group carefully and pick out **ONLY ONE** statement from each group which best describes the way you've been feeling during the last 2 weeks:

- | | |
|--|---|
| <input type="checkbox"/> I am sad once in a while. | <input type="checkbox"/> I feel like crying everyday. |
| <input type="checkbox"/> I am sad many times. | <input type="checkbox"/> I feel like crying many days. |
| <input type="checkbox"/> I am sad all the time. | <input type="checkbox"/> I feel like crying once in a while. |
|
 | |
| <input type="checkbox"/> Nothing will ever work out for me. | <input type="checkbox"/> Things bother me all the time. |
| <input type="checkbox"/> I am not sure if things will work out for me. | <input type="checkbox"/> Things bother me many times. |
| <input type="checkbox"/> Thing will work out for me OK. | <input type="checkbox"/> Things bother me once in a while. |
|
 | |
| <input type="checkbox"/> I do most things OK. | <input type="checkbox"/> I do not feel alone. |
| <input type="checkbox"/> I do many things wrong. | <input type="checkbox"/> I feel alone many times. |
| <input type="checkbox"/> I do everything wrong. | <input type="checkbox"/> I feel alone all the time. |
|
 | |
| <input type="checkbox"/> I hate myself. | <input type="checkbox"/> I have plenty of friends. |
| <input type="checkbox"/> I do not like myself. | <input type="checkbox"/> I have some friends but wish I had more. |
| <input type="checkbox"/> I like myself. | <input type="checkbox"/> I don't have any friends. |
|
 | |
| <input type="checkbox"/> I do not think about killing myself. | <input type="checkbox"/> Nobody really loves me. |
| <input type="checkbox"/> I think about killing myself but I would not do it. | <input type="checkbox"/> I am not sure if anybody loves me. |
| <input type="checkbox"/> I want to kill myself. | <input type="checkbox"/> I am sure that somebody loves me. |
|
 | |
| <input type="checkbox"/> I look OK. | |
| <input type="checkbox"/> There are some bad things about my looks. | |
| <input type="checkbox"/> I am ugly. | |

MY OPINION: I thought question _____ (select either 9A or 9B) was better to ask youth because....

THE END....THANK YOU!

