

Persistent gaps/challenges:

The most frequently identified challenge to disclosure was stigma, stemming from both feared and experienced stigma. Caregivers and HIV-positive young adults repeatedly mentioned fear of mistreatment for themselves and/or their children if community members were to learn of their status. There was general agreement that HIV is not discussed openly in their communities and that this adds to stigma. Caregivers cited a fear of rejection and of being blamed for their condition or their child's as a reason for avoiding HIV-related service programs. However, it is worth repeating that the community and interviewees largely did not associate NACCW and Isibindi with HIV.

GRIEF AND BEREAVEMENT

Current approach/activities:

NACCW identifies support for grief and bereavement as a critical component of its psychosocial support to families. As such, the program offers a variety of activities and support services to bereaved children, adolescents, and adults. These include the development of memory boxes to store keepsakes of loved ones who are gravely ill or who have already passed away. Isibindi also supports bereaved clients through therapeutic activities such as drawing family trees and creating memory books to help them reconnect to experiences with their deceased loved ones. Persona dolls are also used to help children talk about their emotions and problems. These have been used to identify issues around bereavement as well as physical and sexual abuse. Older children may be offered journals and guidance in writing about their emotions, while younger children may be offered play therapy using clay to express their feelings. Through the Adolescent Development Program at Isibindi Safe Park, young people can participate in group activities to help them process their grief, including letter writing and a candle-lighting ceremony in honor of loved ones they have lost. For caregivers, NACCW will provide support in succession planning and preparing for the future of the child.

Good practices in addressing grief and bereavement:

- Numerous activities and strategies to work with children, including memory boxes and books, family trees, persona dolls, letter writing, and group sessions
- Support to caregivers in thinking through future care of the child.

Persistent gaps/challenges:

Overall, NACCW offers a wide variety of methods for helping clients of all ages address their grief. However, it is unclear whether the tools used by CCWs are adequate for identifying the need for grief and bereavement support, and what process is used to determine the most appropriate method for each client.

HIGHLIGHTED TOOLS/RESOURCES

For child clients:

- *My Living Positively Handbook* (Children's Rights Centre)
- Memory boxes and memory books
- Family trees
- Persona dolls

Title	Author/ Publisher	Date published	Summary of tool/resource purpose	Users				Beneficiaries				Subject area				
				HIV + Child	HIV Affected Child	Caregivers	Service Providers	HIV + Child	HIV Affected Child	Caregivers	Service Providers	Capacity Building	Disclosure	Adherence	Stigma	Grief - Bereavement
Information and Action Tool for Supporting Children, Families, and Communities	Human Sciences Research Council and REPSI (South Africa)	2006	Tool helps community workers communicate with supervisors, group leaders, and mentors about the needs of children and families as well as assessing families' capacity to provide psychosocial support.				√	√			√					
Journey of Life	RESSPI	Unknown	Tool designed to encourage reflection, dialogue, and action among all people who interact with children and can contribute to their care, support, and protection. Not specific to HIV-positive children.			√	√	√								√
Kids ART Education Series - The Children's Treatment Literacy Toolkit: Responding to the HIV and AIDS Related Needs of Children in Southern Africa	Southern Africa HIV and AIDS Information Dissemination Service	2008	A treatment literacy toolkit that examines issues around treatment and adherence through games and exercises that target kids. This is targeted toward the developing world context.	√		√	√	√			√	√	√	√		√
Living Positively with Self-Esteem: Experiences of Working with Children Living with HIV/AIDS	Save the Children in Uganda	Unknown	A Case Study of Health Alert in Northern Uganda. Includes disclosure and male involvement.				√	√			√	√				
Living with HIV (Chapter 5 of Caring for Children with Special Needs)	New York State Department of Health	2003	Provides some pointers/guidance for parents of children living with HIV about disclosure; directed towards parents in the United States.			√		√	√			√				
Living with X: A Body Mapping Journey in the Time of HIV and AIDS, a Guide for Facilitators	RESSPI	2007	Body mapping technique manual to do as an exercise with people living with HIV.				√	√			√					

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My Living Positively Handbook	Children's Rights Centre	2006	Tool directed to children to talk about HIV and living positively. Discusses how disease is transmitted, ART, and disclosure; has participatory exercises to facilitate the learning of this information and has an adult-focused complementary tool.	√								√	√				√
Pediatric Disclosure: Talking to Children about HIV	International Center for AIDS Care and Treatment Programs: Columbia University Mailman School of Public Health	Unknown	Guide about the issues and importance of child disclosure; also addresses communication and adherence.				√	√		√		√	√	√			
Protocol for Child Counseling on HIV Testing, Disclosure and Support	Family Health International	2007	Counseling guidelines for children and their parents/guardians about HIV in India. Holistic approach to counseling considering HIV as one among many other issues in a child's life. Includes sections on grief, stigma, and disclosure.	√			√	√				√	√	√	√	√	√
Psychosocial Care and Support Mainstreaming Guidelines	RESSPI	2008	Guide for organizations on how to mainstream psychosocial support. Includes pediatric HIV programs.				√	√				√					
Psychosocial Support Advocacy Toolkit	RESSPI	2008	Toolkit focuses on psychosocial support advocacy to create an environment which protects the rights, health, and welfare of children and young people, whether orphaned, affected by HIV, or victims of war and abuse.				√	√				√					

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Supportive Care Issues for Children with HIV Infection (Chapter 18)	New York State Department of Health AIDS Institute	2001	Gives recommendations to health care professionals on meeting the psychosocial and medical needs of children living with HIV. Includes issues of grief, developmental stages, disclosure, adherence, and HIV affected siblings.				√	√	√		√	√	√		√	
Taking Medication for HIV	Stephen Head	2003	Protocol regarding medication for HIV-positive children; nothing about psychosocial issues.	√				√						√		
Talking with Children, Young People and Families about Chronic Illness and Living with HIV	Edited by Jennifa Miah; National Children's Bureau	2004	Guide for professionals on how to talk to families and children with HIV. Covers issues of disclosure and HIV affected children, developmental understanding of the illness, and disclosure with young gay patients.				√	√	√	√		√	√			
Teen Talk Living with HIV	Lori Wiener, PhD; Lauren V. Wood, MD	2004	This is targeted towards the HIV-positive teenager about issues regarding intercourse and birth control.	√				√				√				
The GHAIN Programme for Orphans and Vulnerable Children: Achievements and Lessons	Global HIV/AIDS Initiative Nigeria (GHAIN)	2007	Gives a description, results/lessons learned, and recommendations for policymakers out of GHAIN's OVC program. Program services included psychosocial support along with health, nutrition, shelter, life skills, and legal support.				√	√	√		√					
The Mental Health Needs of Vulnerable Children and their Caregivers in Low Income Areas; a Training Guide	Brian Robertson; REPSSI	2008	Training guide designed for health care workers who do not have child and adolescent mental health training. It educates caregivers and HIV workers about the emotional development and mental health needs of vulnerable children as essential for their well-being.				√				√					

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The Talking Book: Safe Disclosure to Children with HIV and AIDS	REPSSI	Unknown	Tool for disclosure does not have to be read, a button is pressed on each illustrated page and the book “talks” to the caregiver and guides them how to disclose and explain the child’s HIV status to the child.			√		√				√				
The Tree of Life	Ncazelo Ncube-Mlilo (REPSSI) and David Denborough (Dulwich Centre Institute of Community Practice)	Unknown	The Tree of Life sets out to create safe spaces for children affected by HIV, poverty, or conflict to speak of loss, hope, connection, and courage. It is specifically used as a tool that can deal with loss and bereavement. To be used with groups of children.				√	√	√			√				√
Tracking Your Health: A Guide to Creating a Tracing Book	REPSSI, Canadian AIDS Treatment Information Exchange	2007	Tracing book for HIV-positive children that helps them keep track of their medications and issues related to ART.	√				√						√		
Treatment Issues for HIV-Positive Adolescents	Neal D. Hoffman, Donna Futterman, and Alice Myerson. <i>AIDS Clinical Care</i>	1999	Overview of psychosocial and medical issues and adherence with HIV-positive adolescents for service providers. Includes brief discussion of disclosure, adherence, and grief.				√	√				√	√	√	√	√
Understanding HIV Basics	REPSSI and CATIE	Unknown	Tool integrates psychosocial support issues into biomedical aspects of HIV treatment; deals with adherence to and resistance and side effects of HIV medication.			√		√				√		√		
Weaving Hope for our Children: Home Based Care as an Entry Point for Psychosocial Care and Support for Children affected by HIV and AIDS	REPSSI, Hospice Association of Zimbabwe, and New Zealand Agency for International Development	Unknown	Manual intended to build capacity of the home-based care volunteer so that they can have an increased awareness and understanding of psychosocial issues of children as they go about their work in the home-based care environment.				√	√				√				

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Working with Parents in HIV-Affected Families: A Guide for Providers	National Pediatric & Family HIV Resource Center	2001	Provides providers with guidance around psychological needs (mental health and coping) with HIV-positive children in context of the United States.				√			√		√	√			

	<i>How are children their families equipped to combat external and internalized HIV-related stigma?</i>	
8.	Do you have contact information for these programs?	
9.	What are current gaps in providing HIV-positive children with psychological and social support? (i.e., what is still needed to better equip HIV-positive children, their parents, their caregivers, and/or their health providers in addressing the psychological and social needs of these children?)	
10.	<p>What gender-specific issues are associated with providing psychological and social support to HIV-positive children? (i.e., are there gender-related barriers to accessing or utilizing services, or to providing children with support?)</p> <p><i>Probe:</i></p> <p><i>Are there issues specific to mothers in providing support? Fathers? Female caregivers? Male caregivers? Female health providers? Male health providers?</i></p> <p><i>Because of gender norms, do experiences of children receiving or not receiving support differ based on sex?</i></p>	
11.	If someone else were to work with HIV-positive children 0-12 years of age and their families, what are the three most important psychological and social issues you would recommend that they be mindful of?	
12.	What are the three areas that you believe we need to better understand when working with HIV-positive children to help them have a strong foundation for their psychological and social well-being?	

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AIDSTAR-One

John Snow, Inc.

1616 Fort Myer Drive, 11th Floor

Arlington, VA 22209 USA

Phone: 703-528-7474

Fax: 703-528-7480

Email: info@aidstar-one.com

Internet: aidstar-one.com