

Chapter 31

Family and Community Support***Overview***

Hospice and palliative care programs are challenged to provide and promote circles of support for children, families, and communities that include support at individual, governmental, and global levels. Palliative care programs need to be fully integrated and incorporate advocacy and lobbying for all-around quality services for children and their families. Understanding the total picture ultimately influences governments and affects how service organisations render their services at the family and community levels.

Children are more likely to cope with excessive trauma and loss if they are able to live in familiar surroundings that are stable and nurturing. There is general consensus that orphans should be cared for in family units and extended family networks, and that siblings should not be separated. Institutionalised care on this scale is also not cost-effective. The extended family could possibly take care of these children provided they are adequately supported on all levels.

Empowering families and communities to provide effective care of children is a catalyst for facilitating healing and restoring wholeness to wounded and broken children and, by implication, the rest of society. This singularly important task needs to be tackled collaboratively by governments and organisations so that child-friendly policies and programs, linked to promoting community conversations about the best ways to care for orphans and vulnerable children, become commonplace. There is probably no single intervention more deserving of resources because, as Nelson Mandela frequently says, ‘our children are our future’.

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Global Picture

The HIV/AIDS epidemic has had a staggering impact on the well-being of children, especially those in sub-Saharan Africa (see Box 31.1). In response, in 2001 the United Nations General Assembly Special Session on HIV/AIDS adopted the Declaration of Commitment on HIV/AIDS. The Declaration reflects global consensus on a comprehensive framework for achieving the Millennium Development Goal of halting and beginning to reverse the pandemic by 2015.

The goals of the Declaration are rooted in human rights principles, specifically the United Nations Convention on the Rights of the Child (UN, 1989). The African Charter on the Rights and Welfare of the Child complements the UN Convention by also emphasising the child's responsibilities (OAU, 1990). Broadly speaking, there are four basic rights — the right to protection, development, participation, and survival — which must be applied to all children, including those infected and affected by HIV/AIDS.

The Declaration's signatories committed themselves to:

- Develop, and make significant progress in implementing, comprehensive care strategies to strengthen family and community-based care, including that provided by health care systems and the informal sector; to provide and monitor treatment of people, including children, living with HIV/AIDS; and to support individuals, households, families, and communities affected by HIV/AIDS.
- Ensure that national strategies are developed to provide psychosocial care for individuals, families, and communities affected by HIV/AIDS.

- Develop and implement national policies and strategies to build and strengthen the capacities of government, families, and communities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS, including appropriate counselling and psychosocial support; ensure their enrolment in school and access to shelter, good nutrition, and health and social services on an equal basis with other children; and to protect orphans and other vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking, and loss of inheritance.
- Ensure non-discrimination and full and equal enjoyment of all human rights through the promotion of an active and visible policy of destigmatisation of children orphaned and made vulnerable by HIV/AIDS (UNAIDS, 2003).

Box 31.1

The Impact of HIV/AIDS on Families and Children in Sub-Saharan Africa

In the hardest-hit countries of sub-Saharan Africa, HIV/AIDS has profoundly affected children and their families, causing:

- Increased vulnerability
- Economic hardship
- Lack of love, attention, and affection
- Lack of education
- Loss of inheritance
- Psychological distress
- Increased risk of abuse, neglect, and infection
- Malnutrition and illness
- Stigma and discrimination

Key Interventions for Supporting Families and Communities

Key interventions, developed by the UN and UNICEF, should be integrated at all levels, including prevention. Individual community-based organisations (CBOs), nongovernmental organisations (NGOs), and government structures must define the exact nature of the action they need to take to implement these strategies (UNAIDS, 2003; UNICEF, UNAIDS, USAID, 2003).

1. Strengthen the Capacity of Families to Protect and Care for Orphans and Vulnerable Children.

- Improve household economic capacity.
- Provide psychosocial counselling and support.
- Strengthen and support childcare capacities.
- Support succession planning.
- Prolong the lives of parents.
- Strengthen young people's life skills.

2. Strengthen and Support Community-Based Responses.

- Engage local leaders in responding to the needs of vulnerable community members.
- Organise and support activities that enable community members to talk more freely about HIV/AIDS.
- Organise cooperative support activities.
- Promote and support community care for children without any family support.

3. Ensure Access to Essential Services.

- Increase school enrolment and attendance.
- Register births of all children.
- Provide basic health and nutrition services.
- Improve access to safe water and sanitation.
- Advocate for judicial systems to protect vulnerable children.
- Ensure placement services for children without family care.
- Strengthen district/local planning and action.

4. Ensure That Governments Protect the Most Vulnerable Children.

- Adopt national policies, strategies, and action plans.
- Develop and enforce a supportive legislative framework.
- Allocate adequate resources and ensure their use at the community level.
- Establish mechanisms to ensure coordination of efforts.

5. Build the Capacity of Children to Become Self-Supporting and to Participate at All Levels

- Equip children with life skills.
- Make children aware of their rights.

6. Create a Supportive/Enabling Environment for Affected Children and Families

- Conduct a participatory situation analysis.
- Mobilize influential leaders to reduce stigma, silence, and discrimination
- Strengthen and support social mobilisation efforts at community level.

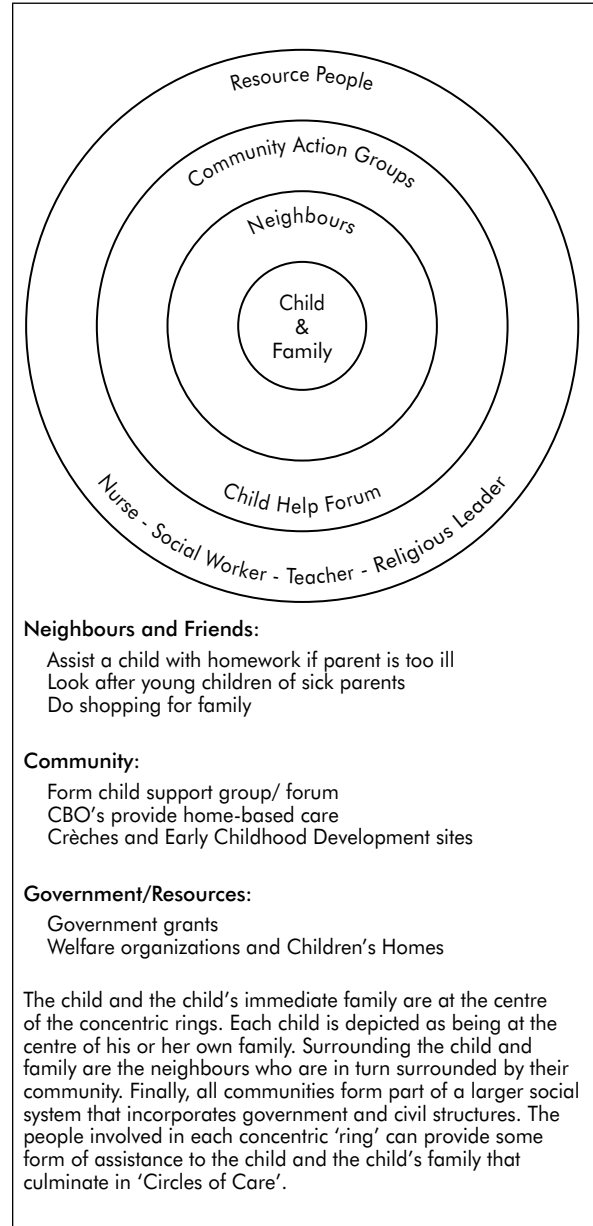
Guidelines for Strengthening Community Support

Children come from a family that forms part of a neighbourhood, neighbours; are a segment of a broader community, which is part of wider society that includes governments, NGOs, CBOs, faith-based organisations (FBOs) and resource groups (Ramsden, 2002). Hospice and palliative care programmes are challenged to promote circles of support using all of these elements (see Figure 31.1)

The following lessons have been learned from numerous small-scale programmes serving orphans and vulnerable children.

- Focus on the most vulnerable children and communities, not only those orphaned by AIDS.
- Define community-specific problems and vulnerabilities at the outset and pursue locally determined intervention strategies.
- Involve children and young people as active participants.
- Give particular attention to the roles of boys/girls, men/women, and address gender discrimination.
- Strengthen partnerships and build coalitions.
- Link HIV/AIDS prevention, care, and support activities to support for orphans and vulnerable children.
- Provide external support to strengthen community initiative and motivation.

Figure 31.1: Community Circles of Support



Source: Children's Rights Centre, 2003.

Psychosocial Support

Psychosocial support is the ongoing process of meeting the physical, emotional, social, mental, and spiritual needs of children (see Table 31.1), all of which are essential elements of meaningful and positive human development (REPSSI, 2003). See Chapter 29: Psychosocial and Spiritual Care for more in-depth discussion of how to work with and counsel children and their families.

Table 31.1: A Simple Model of Psychosocial Support

Emotional	Physical	Social	Spiritual	Educational
Memory work Bereavement Counselling	Food and clothing parcels Assistance with grant applications	Visiting children in their homes	Rituals that help the healing process The power of faith	Helping children remain in school (school fees)

Source: Brakarsch, 2003.

Emotional Support

Grotberg describes resilience as ‘the human capacity to face, overcome and be strengthened by or even transformed by the adversities of life’ (CAFO, 2002). All interventions ought to focus on developing resilience because resilient children are better able to cope with life’s adversities.

Factors that help children cope:

- Understanding an adverse event
- Belief in themselves
- Knowing that they have some control over what happens
- Giving deeper meaning to an adverse event

These capabilities are usually developed in children by age 15 and are facilitated by external and internal resources as depicted in Table 31.2.

Resilience is developed by:

- Providing a safe, nurturing environment in which the child’s needs are met
- Spending time with the child, listening, and showing interest in what she or he does, thinks, and feels
- Teaching children how to communicate
- Allowing for mistakes
- Involving the child in day-to-day activities
- Teaching the child family routines
- Praying with and for children
- Acknowledging children for what they are, not only what they do
- Trust

Table 31.2: External and Internal Resources that Develop Resilience in Children

External Resources	Internal Resources
<ul style="list-style-type: none"> • Close, secure relationship with caregiver • Close relationship with remaining relatives • Education • Financial stability • Close links with cultural community 	<ul style="list-style-type: none"> • Wide range of emotions • Sense of belonging • Interest in others • Value and belief system • Creativity, innovation and curiosity • Self-confidence

Source: Mallman, 2002.

Physical Support

Medical Care and Palliative Care

Children who are infected with HIV need regular and ongoing primary care (see Chapter 27). They also should be provided palliative care, including home-based care if needed. Where available, antiretroviral therapy (ART) should be made available to children in conjunction with holistic care programmes (see Chapter 28).

Children under six years of age are generally entitled to free primary health care at clinics and state hospitals.

Material and Food Assistance

The distribution of food, clothing, and toys to families in need forms part of the holistic care a palliative care organisation attempts to provide. In particular, nutrition and HIV/AIDS operate in tandem at the individual and social levels (see Chapter 19: Nutrition). Undernourished people are susceptible to infection. Nutrition is also linked to treatment adherence, and will have even greater significance once ART is made accessible. Children can be taught how to grow their own vegetables in communal vegetable gardens. In addition to being a source of nutrition, this provides them with an opportunity to develop a sense of achievement and self-worth. Income generation projects represent one strategy to promote food security and are well within the scope of smaller NGOs.

Programs should establish a resource list that includes large NGOs, FBOs, and private businesses that are sources of bulk food or are able to warehouse and distribute it to organisations that visit families in their area of operation. Service organisations such as Rotary and Round Table can be engaged to support such activities.

Accessing Welfare Grants

Few countries in Africa have a social security system that provides a grant for the child or for the person caring for or fostering the child. Organisations dealing with children and families should stay informed about any available welfare support available to vulnerable children. For example, in South Africa, where welfare grants are offered by the government, frequent policy changes necessitate regular contact with relevant authorities in order to keep abreast of the current value and application procedure. A birth certificate is a prerequisite for the submission of a grant application — and many children do not have one.

Partnerships between NGOs and relevant government departments can speed up the process of accessing documents and making applications for assistance (see Chapter 24: Financial and Legal Issues). NGOs and service organisations can facilitate access to documentation by bringing social workers with the necessary knowledge and expertise to process documentation for large groups of children at one time.

Social Support

Child-headed Households

Usually relatives in the extended family take over the care of children after their parents die. In many cases, it is assumed that the grandmother will care for the child, but evaluation of the grandmother's situation may show she is too old, has many other grandchildren in care, lives in poverty, or is in poor health. One of the tragic outcomes of the HIV/AIDS pandemic is the fact that as families are no longer able to absorb the burden of so many deaths, child-headed households have become relatively commonplace. Children in these circumstances require additional support in all spheres of their lives. NGOs and FBOs are in a good position to offer them support.

Optimal Placement of Orphans and Vulnerable Children

In countries where welfare placement agencies exist, it is imperative that home and palliative care programmes develop sound partnerships with them. In South Africa, until a vulnerable child or orphan is officially placed, she or he has no security in terms of legal status. One way of speeding up an often long-winded process is to alleviate the workload of state social workers by doing as much of the background investigation and paperwork as possible.

In South Africa, it has been observed that starting children on antiretroviral therapy sometimes has the effect of stimulating the welfare staff in children's homes to trace blood relatives. Such children are being returned to their families.

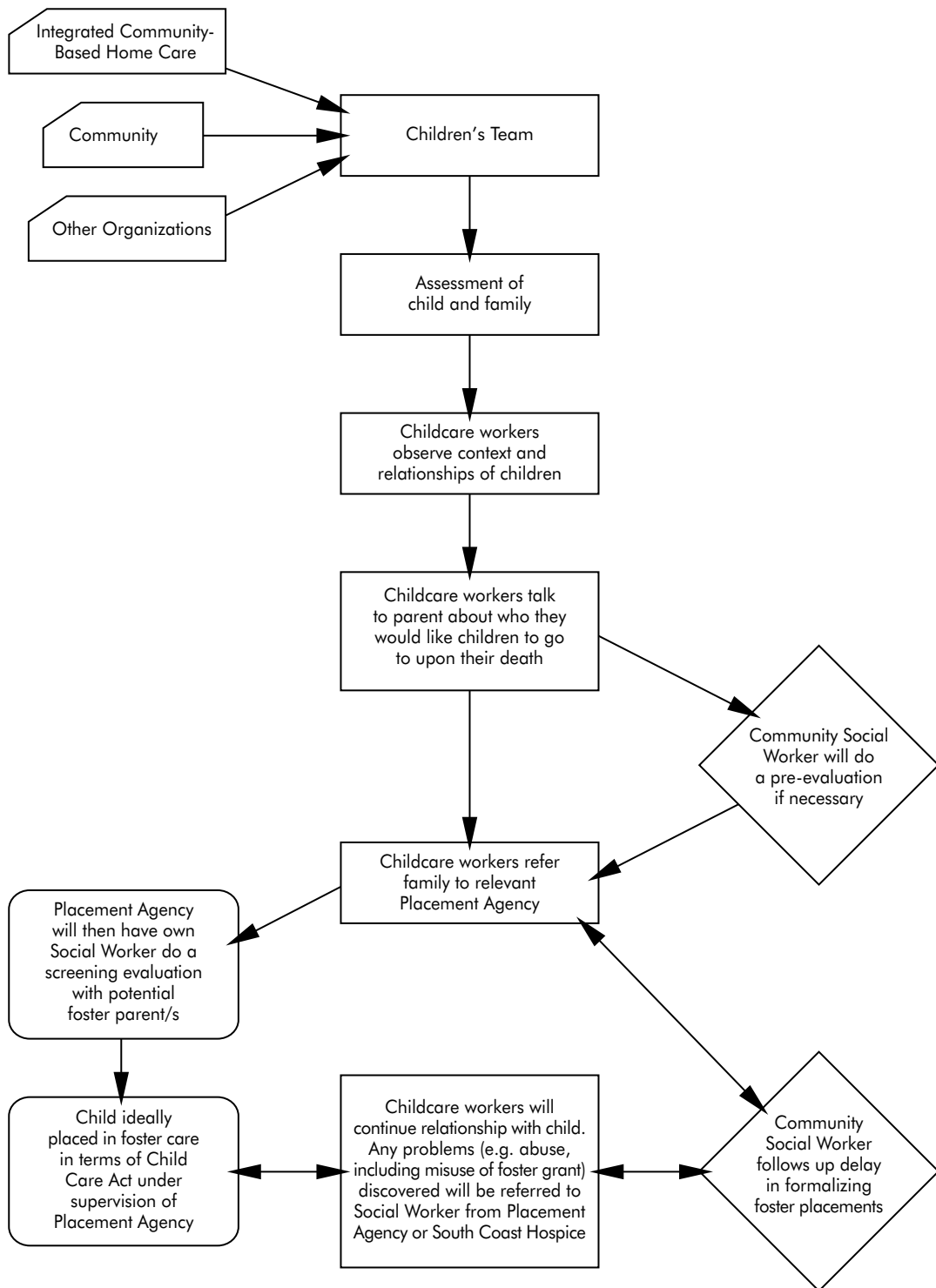
It is essential also to identify orphans and potential foster parents or caregivers as early as possible. This allows the dying parent to participate in the process. Knowing who will care for their children often helps parents to die in peace.

Figure 31.2 depicts an example of an optimal placement process. Although the flow chart focuses on foster placements, this process can also be used to identify other types of potential caregivers whilst the parent is still alive but too ill to care for the child.

Guardianship

It is increasingly common to find children living in child-headed households, or in the care of adults who are not their legal guardians. Neither chronological age nor physical development are fail-safe indicators of psycho-social maturity or the capacity to manage a household, to adhere to a taxing therapeutic regimen, or to give appropriate and informed consent for an intervention. In cases where a child-headed household is identified and no other source of care is available, efforts to support the household should focus on developing and strengthening a local safety net through home-based care. It is usually not in the interest of the child or the household to assume independent capacity to cope. There are, however, some remarkably resilient children who are coping more than adequately.

Figure 31.2: Flow Chart for Placement of Vulnerable Children



Source: Juliet Carter, 2004. Courtesy of South Coast Hospice, KwaZulu Natal, South Africa.

Spiritual Support

Hospice philosophy affirms both life and quality of life. No one has the right to take away hope from a child or an adult. Hope is sometimes all a child has left to cling to in the face of overwhelming loss and suffering. The child needs to make sense of and find meaning in her or his suffering. This is directly related to developing resilience in the child.

Educational Support

Education

Children have the right to education. Communities at all levels can assist children with their schooling by recycling secondhand uniforms, stationery, and books. Groups can organise bursaries, feeding schemes, and help for children with homework.

Advocacy

It is important to know the law to be able to advocate for children. For instance, the South African Schools Act (84 of 1996) Section 39(4) and Namibian law clearly spell out the rights of a child to a free basic education. The South Africa Department of Labour offers free vocational training courses for unemployed persons over age 16.

Advocacy also plays a central role in the other areas of support, such as lobbying for access to ART, food security, and adequate shelter. Reducing the stigma attached to HIV/AIDS is also a key component of advocacy.

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