Recognition for Home-Based Carers

HIV and AIDS have placed a great strain on the health sector, resulting in new care needs and a crisis in health and other services. The Government has embarked on a programme of re-engineering primary health care (PHC) to create a more efficient and cost-effective health system in South Africa. At the forefront of this is a cadre of people, mostly women, who provide home-based care in communities. In many cases, these workers are not consistently and appropriately recognised and the current Home-Based Care Policy isn’t clear about the future of these hard-working, unsung heroes.

HIV and AIDS have placed a huge strain on South Africa’s already-struggling health system. Disrupted family and community life, not enough health professionals and facilities, combined with very high rates of unemployment and poverty, precipitated a move towards home-based and community care. (Hunter, 2005)

Primary Health Care re-engineering
The challenges prompted the National Department of Health to overhaul our health system to:
1. Increasing life expectancy
2. Reduce maternal and child mortality rates
3. Combat HIV and AIDS and decrease the burden of disease from TB.
4. Strengthen the effectiveness of the health system. (Negotiated Service Delivery Agreement, 2010)

“Home-based personal care workers provide routine personal care and assistance with activities of daily living to persons who are in need of such care due to effects of ageing, illness, injury or other physical or mental condition in private homes and other independent residential settings.”

– QCTO and Health & Welfare SETA recently agreed definition for a Residential Care Officer

Primary Health Care (PHC) re-engineering aims to strengthen local health systems with an emphasis on prevention and promotion of primary health within the district health system.

A cadre of carers
Central to this plan is a cadre of people called Community Health Workers (including Home-Based Carers and Community Care Workers) who will conduct screening and surveillance of households as members of a primary health care outreach team. As ‘lay’ care givers, their work includes home visits to perform clinical tasks, such as administering pain relief or medication, as well as seeing to the social, psychological and emotional (psychosocial) needs of households.

The Department of Health estimates there are between 60,000 – 70,000 of these workers who are mostly volunteers managed by non-profit organisations and paid a nominal stipend rather than a salary. These organisations are often funded by the state but many must also raise their own resources. Community Health Workers will be employed by the state from this pool.
Those not employed by the state will remain focused on home-based care, but with little formal training, employment prospects or defined career path.

**Unsung heroes**

While the re-engineering of primary health care recognises the vital place of home-based care, the Home-Based Care Policy isn’t clear about the future of these workers within the new PHC framework. There also appear to be challenges with leadership and capacity in organisations which manage home-based carers.

While appropriate qualifications, a curriculum and job description for Community Health Workers have been established, no such clarity exists for Home-Based Carers. NACOSA, through the Joint Primary Health Care Forum (JPHCF), is actively involved in the development of a curriculum for Home-Based Carers, with the buy-in of the Department of Health.

**Experience and expertise**

Home-based caregivers have been at the forefront of the AIDS crisis from the start, providing care and support to family members and neighbours.

Over time, community carers have developed a tremendous amount of expertise in caring for people with HIV and AIDS in impoverished and isolated communities. They provide this care despite extreme shortages of supplies and compensation, poor sanitation and transportation challenges. Their work continues unnoticed and is hardly rewarded, leaving many to suffer physically and mentally.

“We are working so hard, we make sure we do our work perfect but no one sees that. Yes, we are volunteers but we need someone to say thank you for what we are doing.” – Home-Based Carer

**Overlooked and under-valued**

While home-based caregivers continue to provide most of the care and support for those living with HIV and AIDS, the majority of programmes and policies are designed, implemented and monitored without their vital experience and perspectives.

The employment conditions of home-based carers vary considerably and the laws, regulations and codes applying to them are unclear. Although they are expected to work fairly regular hours, with specific tasks to perform, they are still not regarded as employees and are generally very poorly paid, if at all. Because they work for organisations that have their own funding challenges, they have little job security and few professional development opportunities.

*Community Health Workers screen, map, educate, link and grow the primary health model in the community for which they are responsible.*

*Home-Based Carers are involved on a deeper and more intensive level of home care of individual community members.*

The distinct experience and competencies of the Home-Based Carer are in danger of being lost, despite the overwhelming need for this type of care. NACOSA and the JPHCF believes there is a definite place for Home-Based Carers to work with, but separately to, Community Health Workers to deliver effective, efficient and compassionate care to those who need it most in communities.
Four key issues need urgent attention:

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<thead>
<tr>
<th>Icon</th>
<th>Issue</th>
<th>Description</th>
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<tbody>
<tr>
<td><img src="image1.png" alt="Recognition" /></td>
<td>Recognition and respect</td>
<td>Home-based carers should be professionally recognised for the vital work they do and properly consulted on policy.</td>
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<tr>
<td><img src="image2.png" alt="Role" /></td>
<td>A clear role</td>
<td>A clear role for home-based carers and how they fit into the district health system must be defined and applied to all health authorities in the country.</td>
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<tr>
<td><img src="image3.png" alt="Fair Conditions" /></td>
<td>Fair conditions of employment</td>
<td>Fair conditions of employment: a defined scope of employment with standardised remuneration and conditions should be developed.</td>
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<tr>
<td><img src="image4.png" alt="Training" /></td>
<td>Training and professional development</td>
<td>Training and professional development – the Home-Based Carers qualification and curriculum development process must begin urgently.</td>
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What can you do?

Home-Based Carers need to be recognised as valued contributors to the delivery of comprehensive home and community-based services in partnership with government and non-profit organisations. Their experience of dealing with the ravages of HIV and AIDS in communities should not be lost to the health system and they should be afforded the same employment rights as any other worker in South Africa.

NACOSA’s advocacy activities are therefore geared towards facilitating a consultative process to influence policy development on the status and treatment of Home-Based Carers, who remain the backbone of our primary health care system.

Visit nacosa.org.za or follow @NACOSANet to get involved.

Sources:
- The Joint Primary Health Care Forum (JPHCF), *Home-Based Carers Occupation Curriculum Development Rationale*
- Hospice Palliative Care SA, *Community Health Workers and Home Based Carers Community Care Worker Management Policy Framework: Draft 6*
- Photographs by Simone Scholtz for GreaterGood South Africa.