

# Caring for the caregiver: A framework for support

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**T**he health and well-being of caregivers is the single most important contributor to ensure child health and survival, and to create conditions that enable children to meet their developmental potential. Yet caregivers living in adverse conditions face a broad range of challenges that may affect their ability to be effective parents and to promote early child development.

Providing support to caregivers from pre-pregnancy through childhood must therefore be part of an essential package of services and support (see the essay on pp. 26 – 33). This essay highlights the importance of such support and addresses the following questions:

- Why are caregivers important for children's development?
- How does adversity impact on caregiving?
- What support do caregivers need?
- How can support for caregivers be strengthened?

## Why are caregivers important for children's development?

Young children are dependent on others for their survival and well-being, and need adequate food, warmth, shelter and a clean, healthy environment. In addition, caregivers play a key role in ensuring that infants and children receive care that is sensitive to their developmental needs. More than four decades of research has conclusively shown how sensitive caregiving, characterised by responsiveness and the ability to follow a child's interests and activities without the caregiver imposing their own agenda or taking over the interaction (low intrusiveness), has substantial benefits for the mother–infant relationship and for infant and child development<sup>1</sup> (see the essay on pp. 62 – 65).

Sensitive caregiving is associated with reduced behavioural problems,<sup>2</sup> improved social functioning, better relationships with peers,<sup>3</sup> and enhanced school performance<sup>4</sup>. Warm, sensitive and non-intrusive caregiving helps children to regulate their behaviour and emotions, and provides the foundation for the development of positive problem-solving strategies. When such parenting is not available because of caregiver depression, absence, maltreatment or illness, infants and young children may fail to develop secure attachments<sup>5</sup>, leaving them particularly vulnerable to the effects of negative environments<sup>6</sup>.

It is important to stress how infants and children influence the interaction with their caregivers. Infant temperament and other

characteristics may make some children more difficult to parent. This places additional strain on what may already be a vulnerable caregiving system, and may result in negative caregiving practices that further compromise development. So, for example, a young infant who has severe colic will put a poor single parent under extreme stress, whilst the very same infant in an environment with social support and sufficient financial resources may be engaged with in quite a different way, and with different outcomes. What is clear, however, is that nurturing and sensitive parenting – that is responsive to children's needs – can protect infants and children against the impact of even the most stressful environments, and is therefore essential to ensure optimal child development.

## How does adversity impact on caregiving?

Caregivers living in poverty face a broad range of challenges that may affect their ability to be effective caregivers and to promote good child development outcomes. These challenges include material deprivation, low levels of education, lack of access to jobs and services, social isolation, mental and physical ill health, and domestic violence.<sup>7</sup> Caregivers in South Africa face intersecting epidemics of HIV, alcohol, drug abuse and undernutrition compounded by non-communicable diseases and poor access to basic services and educational opportunities.

South Africa has the highest documented rate of Foetal Alcohol Syndrome (FAS)<sup>8</sup> and children with Foetal Alcohol Spectrum Disorders (FASD) are likely to have a variety of concentration and behavioural difficulties.<sup>9</sup> Rates of FAS are as high as 41 – 74 per 1,000 children.<sup>10</sup> The addition of children diagnosed with partial FAS reveals rates between 68 – 89 per 1,000. Similarly high rates have been noted in two cities in the Northern Cape, reaching levels as high as 67 per 1,000 for FAS and 100 per 1,000 for partial FAS.<sup>11</sup>

South Africa has the highest number of persons known to be living with HIV globally (5.2 million).<sup>12</sup> It has been estimated that by 2015 there will be 2.2 million maternal AIDS orphans in South Africa,<sup>13</sup> many of whom will be cared for by elderly grandparents<sup>14</sup>. Globally, women are the primary caregivers of children and spend more time on domestic tasks and care work than men.<sup>15</sup>

In South Africa, low birth weight rates are high. These children may show less interest in exploring their environment, be less vocal and less happy<sup>16</sup> and may have lower cognitive scores at ages two and three years – all factors that contribute to greater stress in early caregiving.

<sup>i</sup> Attachment is the affectional bond between a child and their caregiver. Securely attached infants are able to freely explore in the presence of their caregiver, and when separated will become appropriately upset, but the caregiver will be able to soothe them, allowing the child to explore once more.



Philani Mentor Mothers visit homes and support mothers and children in their community.

Parenting children with serious illness, injury, disability and emotional and behavioural difficulties can result in higher levels of psychological distress in caregivers. A lack of material and social support and poor access to appropriate services escalates caregiver stress.<sup>17</sup>

All these factors are either related to poverty or exacerbated by it, and in turn may impair infant and child functioning.

### What support do caregivers need?

The increasing use and popularity of the term “the first 1,000 days of development”<sup>ii</sup> have garnered greater attention from policy-makers to this crucial period in children’s development. However, this essay argues that caregivers require support and services throughout children’s lives – including pre-conception, early childhood and the foundation phase of formal schooling. For instance, nutrition interventions with women prior to pregnancy are more strongly associated with foetal nutritional status than nutritional interventions during pregnancy,<sup>18</sup> while there is substantial evidence that significant brain development continues well into adolescence<sup>19</sup>.

### The potential of antenatal care

During pregnancy, one of the main sites of support is antenatal care. South Africa’s antenatal coverage is good: 95% of pregnant women attend an average of four antenatal clinic visits.<sup>20</sup> However this masks the fact that coverage is significantly lower in rural areas.

Only 40% of expectant mothers receive antenatal care before 20 weeks which results in lost opportunities for early identification and clinical management of foetal abnormalities, HIV, anaemia, and hypertension.<sup>21</sup> The extent to which high antenatal coverage can be harnessed in order to deliver additional interventions (without over-burdening existing cadres such as nurses) such as psychosocial support requires exploration (see the essay on pp. 50 – 55).

### The role of community health workers

The government is currently implementing a re-engineering of the primary health care system. One of the aims is to improve the link between facilities and the household or community, and to bring skilled community health workers (CHWs) into the formal health system. It is likely that the most vulnerable households in South Africa will only be reached by community-based health workers who, with sufficient support from the health and social service sectors, will deliver essential early interventions. This could include internationally promoted programmes such as the Care for Child Development<sup>22</sup> module of the integrated management of childhood illness programme to promote language and learning during routine health visits (also discussed in the essay on pp. 50 – 55).

### Community-based programmes with potential

Some examples of home-visiting programmes that have the potential to reach the most vulnerable caregivers include the Philani Mentor Mother programme,<sup>23</sup> the Family and Community Motivators of the Early Learning Resource Unit (ELRU),<sup>24</sup> and Khululeka’s Family Home-Visiting programme<sup>25</sup>. Philani community health workers or mentor mothers<sup>iii</sup> deliver home-based interventions that address the constellation of risk factors affecting women and their children. These include interventions to address nutrition, HIV, tuberculosis, maternal and child health, the early mother–infant relationship, maternal mental health and early child development.

Mentor mothers conduct approximately four antenatal visits and up to eight postnatal visits. In situations of high risk or crisis these visits may be increased and extended. Philani also offers a nutrition support programme for all children younger than six years.

The ELRU Family and Community Motivator programme consists of 20 home visits that take place twice a month, monthly workshops with other caregivers and informal playgroups. The programme provides information on accessing social grants and creating safe, stimulating and healthy environments for children, and an opportunity for the motivator and caregiver to play with the child, using locally-made toys.<sup>iv</sup>

The Khululeka Community Education Development Centre offers services such as a preschool enrichment programme (20 week-long workshops over two years); a family home-visiting programme (eight or more visits twice month) focusing on access to social grants, health and nutrition, and caregiver support; and an infant and toddler support programme for caregivers of children aged

ii From pregnancy through to the end of the second year of life.

iii Mentor mothers recruited by Philani live in the same poor neighbourhood as the caregivers receiving the intervention, yet have children who are thriving. For more information, see: [www.philani.org.za](http://www.philani.org.za).

iv For more information, see [www.elru.co.za](http://www.elru.co.za).

0 – 6 years (weekly group sessions for between 16 – 19 weeks). All three programmes provide generalised counselling to caregivers in one form or another.<sup>v</sup>

The Philani intervention has been shown to have significant benefits for mothers and infants in the areas of children's health and cognitive intelligence, and maternal adherence to health care and HIV prevention strategies. It also benefitted particular subgroups – such as HIV-positive caregivers adhering better to the prevention of mother-to-child transmission tasks. Similarly, caregivers using alcohol during pregnancy reduced their episodes of drinking, especially those women who drank heavily.<sup>26</sup> In a recent evaluation of Khululeka and ELRU, their home-visiting programmes were found to improve parenting, caregiver coping, affectional care, academic and language stimulation as well as improving safety and hygiene in the home.<sup>27</sup>

The extent to which all these programmes can feasibly and cost-effectively be scaled up nationally remains to be established.

### Mental health screening and referral

The programmes above follow a generalised community-based approach. The Perinatal Mental Health Project (PMHP), illustrated in case 7, is an example of facility-based approach. In a re-engineered primary health care system, programmes such as the PMHP would offer a more targeted service to support women with mental disorders. The feasibility at scale and cost effectiveness of using trained counsellors need to be established, but the principle of screening and referral for maternal mental disorders should be a core component of any system that supports caregivers.

### Social support services

Caregivers also require social support and protection. The Children's Act<sup>28</sup> provides for a range of mandatory prevention and early intervention programmes that encourage parenting education, caregiver support and well-being, including access to basic necessities. Caregivers may need support to get social grants, identification documents, and access job creation programmes, for example. Other areas of support include capacity-building to enhance job and life skills, and interventions to address domestic violence and other social problems (see the essay on pp. 62 – 65).

### A multisectoral approach

Multisectoral coordination and engagement are central. One example is the Thusong Service Centres<sup>vi</sup> (formerly known as Multi-Purpose Community Centres) that bring together the departments of Home Affairs, Labour, Health and Social Development, and the South African Social Security Agency. Another is the location of Home Affairs and Social Security officials within maternal obstetric units to ensure that child grant application procedures can take place in one setting immediately after birth, thus improving access to child grants for those who may be eligible.

## How can support for caregivers be strengthened?

The care and development of children is the responsibility of both the public and private spheres – including the family and extended family networks, as well as the health system, early childhood education centres, and the formal schooling system. While maternal and child health has in recent years received significant attention,<sup>29</sup> the focus has been on mortality and morbidity, and less on the broader components of caregiving such as mental health, social and emotional support, accessing social grants, and parenting skills. A continuum of care provides a useful way of considering care across the life cycle, within different contexts.<sup>30</sup> This is illustrated in figure 7, which outlines a (non-exhaustive) list of essential interventions that are needed to support caregivers across the continuum.

Depending on the context, different cadres of workers would be responsible for delivering services across this continuum of care. In South Africa, most women deliver within health facilities and therefore nurses are the primary cadre at birth and at facility level. In terms of community-based postnatal care, community health workers are increasingly being seen as the primary interface.

### Creating an enabling environment

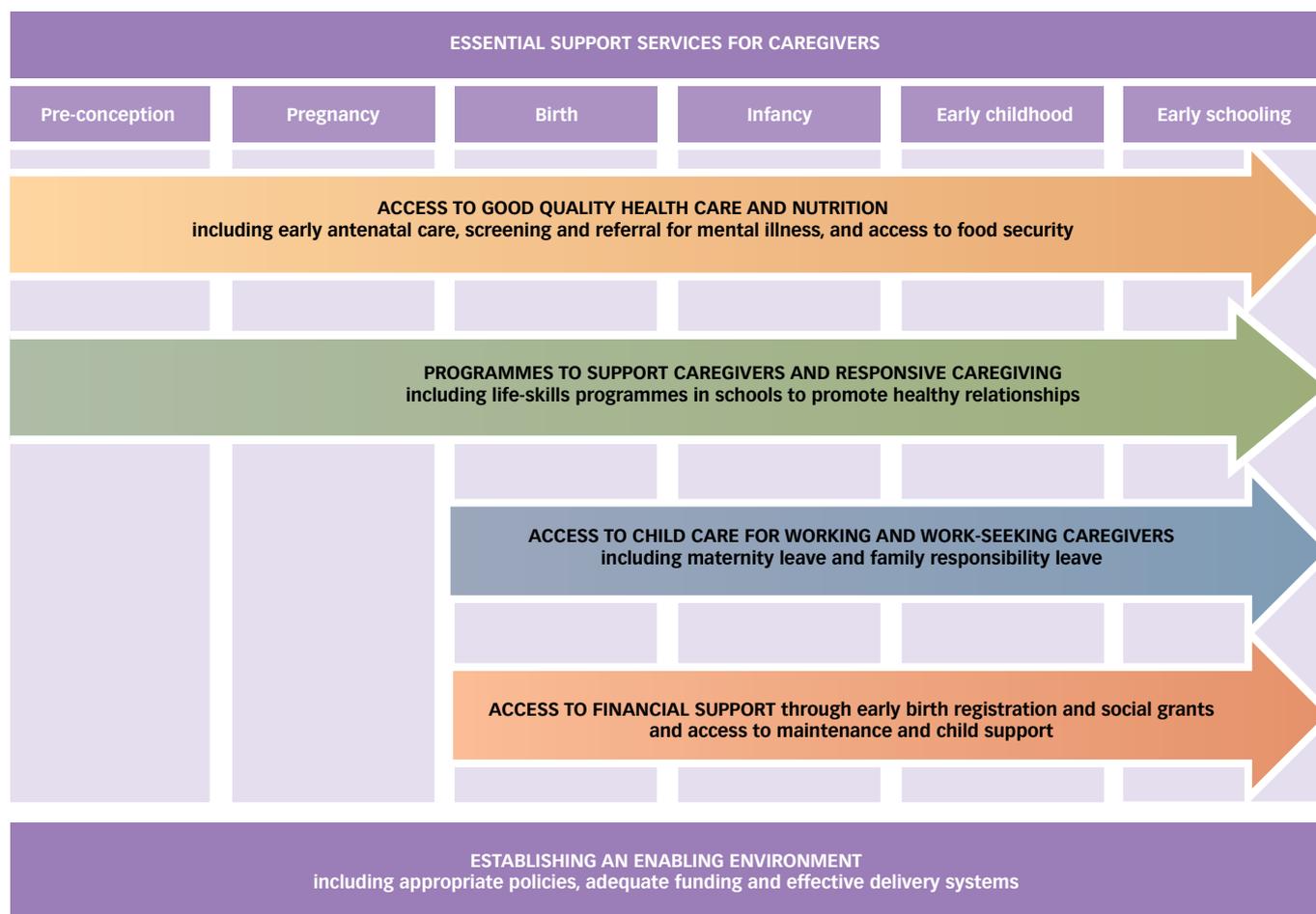
Effective scale-up of community health worker programmes (who are central to the primary health re-engineering strategy) has met many challenges. Large-scale CHW programmes have been marked by high levels of attrition in countries such as Bangladesh, Senegal and Nigeria – often related to low pay (volunteerism in many cases), but also to factors such as poor selection, family disapproval and moving on to better-paid positions elsewhere.<sup>31</sup> Infrequent and poor quality supervision has also undermined many large-scale programmes.<sup>32</sup> This is less likely in smaller initiatives where supervision is often more intense and consistent.<sup>33</sup> While the use of CHWs has achieved many successes,<sup>34</sup> the system has been characterised by the lack of consistent supervision, heavy workloads, low pay (if at all) and poor linkages to the central health system<sup>35</sup>. These are significant barriers and the degree of control and oversight that is possible in small-scale studies does not necessarily translate to the implementation of large-scale interventions, which is a key barrier to sustained impact. An important part of this process lies in building effective strategies to support the management and supervision of CHWs to ensure quality of implementation.<sup>36</sup> Finally, efficient referrals and the management of transitions across and between services are key.

There are a number of systemic functions that create an enabling environment and facilitate the successful completion of tasks across the continuum of care (see the essay on pp. 34 – 43). Establishing an enabling environment is, in the first instance, a function of government and there are three main levers that contribute to this.<sup>37</sup> These levers, as described on the opposite page, are essential but can only be realised in the medium to long term.

v See [www.khululeka.org.za](http://www.khululeka.org.za).

vi See [www.thusong.gov.za](http://www.thusong.gov.za).

Figure 7: Support and services across a continuum of care



1. An appropriate legal framework that provides support to caregivers across all domains, such as social assistance, maternity leave and quality child care. This would include the implementation of child-focused legislation such as the Children’s Act to provide care and protection of children in a developmental way with an emphasis on the continuum of care.
2. The availability of adequate financing and monitoring systems. Part of the solution is simply fiscal (more money should be spent in traditionally neglected areas), but equally important is the better redistribution and use of existing resources.<sup>38</sup> Adequate financing of standard CHW visits coupled with the establishment of a robust national data system on postnatal care (whether in the home or in the facility) are essential. Another component is quality and appropriate supervision and management systems.
3. The final lever is that of inter-sectoral coordination. In South Africa, as in many other countries, roles and functions that are intrinsically linked in the everyday lives of caregivers are in fact artificially split across government departments. For example, social grants are managed by the Department of Social Development while many other support or clinical services are driven by the Department of Health. The result may be a “silo” approach to service provision and costly task replication resulting in missed opportunities to deliver essential services. In a financially constrained system, improving inter-sectoral

coordination is vital, particularly as support for caregivers cuts across numerous systems such as Health, Social Development and Education.

Even with the most efficient, well-functioning system the issue of implementation is core. This would include coverage and equity and the extent to which the most vulnerable and at-risk caregivers are reached by interventions. Even when community-based interventions reach vulnerable populations there are frequently unforeseen barriers that make the actual delivery at the household difficult. These include attitudes and beliefs of family members, as well as family members acting as gatekeepers and controlling key aspects of programme delivery, including the focus, meeting times and duration of CHW visits.<sup>39</sup>

### Creating the impetus for change

Ensuring the well-being of caregivers in conditions of poverty and limited resources will require systemic responses across multiple domains. The following three actions are critical in order to provide the impetus for wider change.

1. A commitment to scale up CHW programmes is essential. The current re-engineering of the primary health care system with its significant focus on CHWs offers a potential avenue for scaling up home-visiting programmes, circumventing the current lack

## Case 7: Caring for mothers – a case for maternal mental health

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The most effective and cost-efficient time to intervene for early childhood development is before birth and in the early years of life.<sup>39</sup> The Perinatal Mental Health Project (PMHP) provides maternal mental health services that are integrated into routine antenatal care.<sup>40</sup> The interventions are located in primary level antenatal care settings. This enhances efficiency as vulnerable women are reached when and where they access health services. The approach is particularly relevant because postnatal care coverage in South Africa remains poor, yet antenatal care coverage is extremely high.<sup>41</sup>

PMHP services are based at three obstetric facilities which provide primary level care, in Cape Town. Service integration requires considerable preparation of the environment. Thus, the project conducted a careful process of developing buy-in and commitment from front-line health workers, and provided capacity-building. On-going engagement and support are also required.

### Screening

Midwives and other clinic staff are trained to screen women for risk for and symptoms of depression and anxiety. This takes place during the first antenatal visit. Eligible women are offered referral for on-site counselling. Counselling appointments are made to coincide with subsequent antenatal visits or when convenient for the women.

### Counselling

Individual counselling is provided free, on an appointment basis, during pregnancy and up to one year after the birth. Women receive an average of three sessions. A full-time clinical psychologist coordinates the clinical services, counsels clients with complex problems, and manages the counselling team. Other members of the counselling team are three trained counsellors and a psychiatrist who works on a part-time basis. The PMHP counsellors are integrated into the obstetric service and are considered part of the maternity care team.

Counselling sessions can assist women with difficult relationships, unhealthy thinking, overcoming losses, and problem-solving. Women with alcohol and substance misuse problems are referred to the hospital's social worker for further intervention. The counsellors collaborate, as required, with psychiatrists, mental health nurses, social workers and allied health workers. Care is frequently supplemented by non-governmental organisations.

Women receive consistent and structured follow-up including phone calls to those who miss appointments or are unable to

attend appointments. All urgent cases, such as psychoses, are referred to tertiary facilities. Ongoing supervision, debriefing, training and feedback are provided to both obstetric staff and PMHP counsellors.

### Postnatal follow-up care

Every woman counselled receives a routine follow-up phone call between 6 – 10 weeks after birth. This structured interview includes questions about the birthing experience, adjustment to life with the baby, the experience of counselling, and whether she needs further intervention. This contact often takes the form of a telephonic counselling session which is useful for women who are unable to access the service but who still require follow-up care.

### Phumza's story

Phumza<sup>vii</sup> was abandoned by her baby's father when she became pregnant. She discovered she was HIV positive and was scared her baby might be affected. At her first antenatal visit, Phumza was offered mental health screening and referred for counselling. After her baby was born, Phumza lost her job and grew more desperate about her financial situation:

*I don't know what is wrong with me. My memory is very poor. On Monday I lost money in the taxi. Yesterday, I lost my jacket. I don't know what I'm doing these days. And I'm sad. Maybe this virus works in my mind, and I'm suffering. I'm always thinking about my future and my children. What if I can't take care of them?*

When she sent a text message to the PMHP counsellor – "I just want it all to end" – the support system kicked in. The PMHP counsellor began providing telephonic counselling, arranged for Phumza to receive medication for her depression, and referred her to her local clinic for on-going psychiatric care. She also introduced Phumza to a community project that helped with food and child grants.

These interventions have resulted in improvements in Phumza's life. Although there are still many challenges, she feels better able to cope and care for her children.

*The PMHP is a partner of the Alan J Flisher Centre for Public Mental Health at the University of Cape Town. The project also engages in training, research and advocacy to take maternal mental health services to scale. For more information, see: [www.pmhp.za.org](http://www.pmhp.za.org).*

vii Not her real name.

of coverage, and providing sustainable interventions for all families and children.

2. Caregiving in contexts of high adversity is extremely stressful. Improving awareness of the signs of caregiver burden and appropriate referrals amongst health care staff, CHWs, early childhood development and social service practitioners should improve caregiving and mitigate the negative impact of poor caregiving on child development.
3. Pregnancy and infancy are critical developmental phases with lifelong consequences, and small changes that become habits can have substantial impact over a lifetime. Ensuring that services such as the PMHP are integrated within existing services together with the cost-effective use of cadres of staff such as counsellors will strengthen coverage and reduce the impact of poor maternal mental health on caregiving practices.

## Conclusion

Caregivers require supportive (albeit different) interventions across a child's life cycle. It is vital that the government focuses on a life-cycle approach that includes screening for maternal mental health; appropriate services for referral; centre- as well as home-based parenting and other supportive interventions; quality early learning opportunities (centre- and home-based); and a commitment to providing good quality child care in order to reduce the burden of care.

The re-engineered primary health care model that is currently being piloted has the potential to meet some of these needs, but will need significant re-modelling and a broader conceptualisation of care and support services. Success will depend on what happens in the household in combination with responsive and supportive health, education and social service systems.

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