Expanding the care continuum for HIV/AIDS: bringing carers into focus

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This review explores the specific issues that cluster around the provision of ‘care’ in the context of the global HIV/AIDS pandemic. We argue that the economic concept of the ‘care economy’ provides a useful lens through which to view the HIV/AIDS pandemic, as it illuminates the increased labour, time and other demands placed upon households and shows that the assumptions on which norms and expectations of care provision are based are increasingly being challenged. While some strides are being made in policy and programming around HIV and AIDS-related care, much more needs to be known and done to enable individuals, families and households to survive in a world shaken by AIDS. Care, we argue, provides fundamental public goods. A strategy of simply downloading responsibility for care onto women, families and communities can no longer be a viable, appropriate or sustainable response. And this is no less true in this current era of expanding treatment options for people living with HIV and AIDS. Our analysis suggests that there are two distinct but inter-related areas for policy intervention and development. The first concerns international health policy and we argue that the international ‘care agenda’ needs to incorporate an understanding of the care economy into its frameworks and strategies for action, giving particular focus to the caregiver. The second area encompasses a broad national healthcare policy agenda, where a range of public, private and non-governmental sector actors come together with common purpose to ensure that households affected by HIV and AIDS are protected and enabled to survive.

Key words: HIV/AIDS, care, gender, home-based care, caregiver

Introduction

‘Who cares for the carers, and why is it taken for granted that women provide, and will continue to provide, care and support to family members and loved ones, with no sense of the cost and value of this work to society and the economy in general?’ (Berman 2002)

Berman’s question gets to the heart of this paper. When there is a sick or dying person in the house, someone quite literally has to care, whether out of love, duty or simply a lack of options. Indeed, research has indicated that up to 90% of illness care is provided in the home (WHO 2000a; Uys 2003). Although the role that men and boys may be playing as providers of care in the context of the HIV/AIDS epidemic has been poorly documented and inadequately understood, it is generally recognized that women and girls are the principal caregivers in the vast majority of homes and bear the greatest degree of responsibility for the psychosocial and physical care of family and community members.

This review explores the specific issues that cluster around the provision of ‘care’ in the context of the global HIV/AIDS pandemic. We argue that the economic concept of the ‘care economy’ provides a useful lens through which to view the HIV/AIDS pandemic, as it illuminates the increased labour, time and other demands placed upon households,1 and shows that the assumptions on which norms and expectations of care provision are based are increasingly being challenged. Many indigenous social safety nets that underpinned the care economy in the pre-AIDS era and that enabled many households to remain viable in times of crisis are being eroded in highly affected communities. At the same time, because most families struggle without a formal diagnosis of the disease that is affecting them, they do not have ready access to even those health sector initiatives (such as home-based care and other programmes) that could provide vital support.

While some strides are being made in policy and programming around HIV and AIDS-related care, much more needs to be known and done to enable individuals, families and households to survive in a world shaken by AIDS. Care, we argue, provides fundamental public goods. A strategy of simply downloading responsibility for care onto women, families and communities can no longer be a viable, appropriate or sustainable response. And this is no less true in this current era of expanding treatment options for people living with HIV and AIDS. Although the increasing availability of life-saving antiretroviral treatment (ART) is to be welcomed, it is clear that many people will either be unable to access...
treatment programmes, will drop out of programmes, or will fail to respond to available treatment (Wood et al. 2003; Amico et al. 2005; Sabin et al. 2005). Thus, far from obviating the importance of a revitalized and perhaps reconceptualized ‘care agenda’, the presence of ARTs in poor countries serves to underscore it. Our analysis suggests, therefore, that there are two distinct but interrelated areas for policy intervention and development. The first concerns international health policy and we argue that the international ‘care agenda’ needs, as a matter of urgency, to incorporate an understanding of the care economy into its frameworks and strategies for action, giving particular focus to the caregiver. While strengthening community home-based care is one part of this agenda, it is clear that the health sector alone will not be able to fully address the needs of affected families. The second area thus encompasses a much broader national healthcare policy agenda, where a range of public sector actors, in partnership with non-governmental organizations (NGOs), donors and industry, come together with common purpose to ensure that households affected by HIV and AIDS are protected and enabled to survive.

**The care economy in the context of HIV/AIDS**

The unremunerated work undertaken within the home, which ensures the physical, social and psychological maintenance and development of family members, as well as ‘volunteer’ activities in the community that keep the social fabric in good order, are referred to in the economics literature as the ‘care economy’ (see, for example, Waring 1988; Elson 1999, 2002; Azari et al. 2004). This work, performed primarily by women, is critical to productivity in the paid economy because it sustains families, allows children to go to school and frees the time of other household members to generate income. This unpaid work also provides a crucial contribution to the broader social and economic development of a country. Recent efforts to assign a value to unpaid work, in fact, show startling numbers where the total value of unremunerated work performed by women totals around 11 trillion dollars (UNDP 1995).

While there are clearly broad-based benefits of this work, there are also substantial costs, particularly for the women undertaking it. In carrying out this largely unremunerated work, women and girls are often forced to leave paid jobs, schooling and other opportunities, and this care work displaces other health producing activities in the household and community (e.g. Steinberg et al. 2002).

A key issue raised by those who work with the concept of the care economy (e.g. Folbre 1994a,b; Azari et al. 2004; Budlender 2004) is that, despite its value to the wider marketplace, this domain of unpaid labour remains invisible – and is not incorporated into national income accounting systems nor generally included in calculations of a country’s overall Gross Domestic Product (see Azari et al. 2004 for a more detailed discussion of this issue; also Budlender 2004). And if unpaid care work remains invisible, so too does the unpaid care worker. For example, programmers and policy makers often assume that women can allocate their time easily between market work and household production (Elson 1991). It is also taken for granted that women will be the ones to respond to crises or illnesses. And in the current public finance environment, which encourages governments to spend less on social development sectors, a ‘care gap’ has emerged which women frequently subsidize with their own time, energy and resources. This line of argument, therefore, asserts that making this unpaid work (and the unpaid workers) visible is of value to governments and policy makers in order to be able to capture the benefits of these activities, but also to be able to enumerate their costs – so that the unpaid contributions of women to the productive economy can be acknowledged and compensated.

We have found the care economy lens to be useful in seeking to further develop the so-called ‘care agenda’ in HIV/AIDS. As Azari et al. (2004: 37) note: ‘HIV/AIDS highlights, in stark terms, the importance of the unpaid work done by women and demonstrates its undeniable contribution to supporting what are already fragile economies’. In households affected by HIV, the pre-existing care workload is compounded by the additional demands of caring for one or more terminally ill family members – demands that, as we discuss below, are not shared equitably by the formal healthcare sector. Making the carer visible, and bringing her into the focus of national and international HIV/AIDS policies, will enable these policies to provide a truly holistic continuum of care for those living with HIV and AIDS, their families and communities.

One of the ways in which the care economy lens is useful is that it helps to distinguish the care provided in the home by family members from care provided by trained individuals (sometimes paid, sometimes volunteer) who are linked to programmes. Figure 1 shows a household in which the person with HIV and AIDS and his/her family are unlinked to any programme – a situation prevailing in the vast majority...
of AIDS-affected households. The gray circle represents the large universe of care provided by family members within the household. The figures in the white circle represent household members living with HIV and AIDS, and the circle itself represents the large proportion of the household care economy that is devoted to the care of those living with HIV and AIDS.

This household type is unlinked to any formal care programme and has little access to health care facilities. Those living with HIV/AIDS in the home and/or their principle carers are not likely to have obtained a formal HIV diagnosis. For this reason, they may be obtaining medicines and various remedies for symptoms from traditional healers, herbalists and local pharmacies or drug shops. But the family in this situation does not have the resources of time or money to attend formal health care services regularly. While some households will remain in this isolated condition, others will, over time, move in and out of varying degrees of association with programmes and service provision (see Figure 2a–c). It is crucial to note, however, that whether or not they sometimes rely on support from programmes, family members provide the bulk of care, and for the vast majority of AIDS-affected families, these caregivers are not linked to or supported by any formal HIV/AIDS care programme. We refer to this domain as ‘unlinked’ care.

**Challenges of unlinked carers**

There are a great many challenges facing unlinked carers, ranging from burn-out and impoverishment to injury, increased vulnerability to illness and emotional despair (see Akintola 2003, 2004; Ortner 2006). Unlinked care providers receive no training, no support from formal programmes and no concrete inputs such as gloves or medication. These carers lack information about the disease they are managing and how it will change over time. Indeed, many do not know that the loved one in their care has AIDS. In addition, due to HIV/AIDS-related stigma, caregivers may be closed off from social support at the time they need it most. In a study in South Africa (Steinberg et al. 2002), only 35% of people living with HIV reported having experienced a supportive response from their community, with one in 10 recounting hostility and rejection, including outright discrimination. Although the role stigma plays in shaping the care and/or lack of care available to those living with the virus is not new, stigma can prevent unlinked carers from reaching out for support even when it is available in their communities (see Parker and Aggleton 2002; Nyblade et al. 2003; Hong et al. 2004; Ogden and Nyblade 2005).

Caring for a person with HIV/AIDS requires considerable time and other resources, which is compounded in many developing countries by a lack of basic services such as

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**Figure 2a.** Person with HIV receiving some support from CHBC programme. Household remains largely unlinked

**Figure 2b.** Person with HIV receiving facility-based care only. Household remains entirely unlinked

**Figure 2c.** Person with HIV receiving CHBC and facility care. Household, not receiving support, continues to remain largely unlinked
The health sector response

What was once a relatively ‘silent epidemic of HIV has shifted to a visible epidemic of AIDS’ (Russel and Schneider 2000: 1), and out of this visibility an awareness is slowly emerging at national and international levels of the importance of care and an international ‘care agenda’. This awareness parallels an increased understanding of the vulnerability of traditional social safety nets in addressing household care and support needs. A study by Seeley et al. (1993: 122) found that ‘blanket statements about the role of the extended family in Africa as a safety net need to be questioned and assumptions that the extended family will be ready and able to assist sick members, treated with caution’. The extended family, their title suggests, is a ‘safety net with holes’.

The cumulative effects of increasing HIV sero-prevalence in highly affected countries has resulted in unprecedented demands being placed on already under-resourced health care services – services which, in many countries, have been further weakened by health sector reform and structural adjustment programmes (see De Jong 2003; United Nations 2004). It is commonly reported, for example, that in communities in which antiretrovirals (ARVs) are not widely available, 50–70% of all hospital beds are being occupied by people with HIV infection (e.g. Msobi and Msumi 2000; Haacker 2001; Guinness et al. 2002; Shisana et al. 2003). In some countries, the problem is further compounded by high absenteeism and increased death rates among hospital staff (Buvé et al. 1994; Foster 1995; Tawfiq and Kinoti 2003; Narasimhan et al. 2004; WHO 2004; Marchal et al. 2005).

Despite the heavy demands being placed on these weak formal healthcare services, however, it is important to note that this burden reflects only a portion of the total number of people needing care for HIV-related illness. As those obtaining an HIV diagnosis are a minority of the total number infected (UNAIDS 2002), most people living with HIV infection will seek symptomatic relief from pharmacies or treatment from outpatient clinics. As the chronic nature of the illness becomes apparent, many will seek treatment from traditional healers (Carballo and Careal 1988; Carswell 1988; Ankrah 1991; Osborne 1996). Those who know or suspect that they have HIV might also be reluctant to obtain care in the public health sector because of stigma, fear of disrespectful treatment, or merely from their awareness that there is no cure. And many people living in poor countries have inadequate access to services. Therefore, the majority of those affected remain in the community without the benefit of formally organized health care provision and are being cared for by family members at home.

Shifting clinical care to the home and community

In the mid to late 1990s, upon realizing that the public sectors of most poor, highly affected countries were ill equipped to handle AIDS-related morbidity, program- mers and policy-makers considered ways to shift the locus of clinical care from the formal health services to the community. Initial efforts revolved around a principle of hospital-based outreach, whereby hospital staff travelled directly to patients’ homes to provide care. Not surprisingly, however, these programmes were found to be time-consuming and expensive, especially in rural areas (Chela 1995; Hansen et al. 1998).

In many communities, meanwhile, new NGOs sprouted up and existing groups mobilized to provide support to families affected by the disease, in an effort to fill the care gap left by the retreating public sector. These groups were largely unable to provide clinical inputs, instead providing a range of care and support services to affected persons and families, including spiritual and emotional support, assistance with funeral expenses and some basic nursing care. Yet, given their limited resources, many of these community initiatives struggled, their networks and strategies often only able to reach a small segment of the affected population, especially in high prevalence countries.

In response to the growing need for a more programmatic approach to care for persons living with HIV/AIDS, the World Health Organization (WHO), in consultation with a wide group of experts, developed a framework for ‘Comprehensive Care Across a Continuum’ (van Praag 1995; Osborne 1996) – later known simply as the ‘Care Continuum’ (WHO 2000b). The intent of the model was to promote, create and sustain a ‘holistic’ approach to care and support for persons living with HIV/AIDS.
The framework locates the person living with HIV/AIDS at the centre of a wide range of actors who are dynamically linked (Figure 3). The entry point to the ‘continuum’ is voluntary counselling and testing for HIV. ‘Home care’ is one element of this broader system of care provision, and it is an element perceived to be particularly relevant and important in resource-constrained settings (e.g. Osborne 1996; Osborne et al. 1997; Gilks et al. 1998; WHO 2000b, 2002a,c; UNAIDS 2002; UNAIDS et al. 2004).

The ‘care continuum’ represents an important advance in the development of an international care agenda. It provides a framework for the development of a public health sector response, and it attempts to illustrate the need to create linkages between care domains. Viewed through the ‘care economy’ lens, and taking into account the prevalence of unlinked care, however, a number of important weaknesses of the model emerge:

1. Although ‘home care’ and ‘community care’ feature in the continuum, the focus remains on formal health sector interventions, failing to account for challenges to access posed by factors such as poverty and gender.
2. All the steps on the continuum except ‘peer support’ and ‘home care’ indicate who will provide care, while the ‘home care’ domain indicates, rather, what type of care will be provided, thus masking the differential impacts on individuals of providing care in the household.
3. The linkage mechanisms remain poorly defined. The ways in which any given individual moves ‘across’ the continuum are not apparent, and the ‘peer support’ domain is completely unlinked to the rest of the continuum.
4. The ‘care continuum’ focuses solely on the (public) health care sector, yet as the care economy lens illustrates so vividly, the needs of individuals and families affected by HIV/AIDS transcend the health sector, to incorporate a range of public and private sector actors. To be truly holistic, a community-centred and multi-sectoral response to HIV and AIDS care is required.

The community home-based care movement

Even though a programmatic approach to the long-term care needs of people living with HIV/AIDS did not emerge until the mid-1990s, families, households and communities began responding to the crisis long before.3 The core of this response was and remains within affected households themselves – what we have referred to as the ‘unlinked’ domain of care. Outside this core are a wide variety of responses which initially built on pre-existing, or ‘indigenous’, mechanisms for coping with crisis and disaster (Barnett and Blaikie 1992; Foster 2002a), and have included faith-based and other community groups. Indeed, many countries witnessed something of an explosion of small-scale programmes that were, for the most part, under-resourced and many times unlinked to broader sources of support, skills, supplies or training. Many of these programmes relied on the support of volunteers (both in the administration and implementation) who had little time (nor necessarily the expertise or experience) to design, document or evaluate their programmes, much less to seek outside funding and technical support.

Thus the explosion of volunteer and community-based programmes in affected communities has, for the most part, been poorly documented (Barnett and Whiteside 2002),
and has been characterized as ‘unsystematic and needs-based’ (WHO 2002a). In real terms, home-based care coverage in Africa remains low, and most people living with HIV/AIDS continue to be cared for in their homes by members of their own kin network, without the benefit of appropriate clinical care or the support of outside organizations (Gilks et al. 1998). Nsutebu et al. (2001) investigate the low coverage of home-based care programmes in Africa, using two home-based care projects in Zambia as case studies, and find that one of the main reasons behind this low coverage is the limited involvement of government.

In light of these problems, the WHO and other international policy-making bodies have, in recent years, attempted to develop guidelines (WHO 2002b) and frameworks (WHO 2002c) to help national planners create a more systematic response. The Policy Framework for Community Home-Based Care (CHBC) in Resource-Limited Settings is ‘a systematic approach for policy-makers, senior administrators and government decision-makers to follow in developing the overall policies and guidelines for CHBC’ (WHO 2002c: 6). The aim of this framework is to create ‘holistic’ CHBC that would encompass ‘provision of care’, ‘continuum of care’, ‘education’, ‘supplies and equipment’, ‘staffing’, ‘financing and sustainability’, and monitoring and evaluation.

This framework, although again focused primarily on the health sector and without clear guidance on how to incorporate unlinked home-based care into the formal system, represents an important advance, endeavouring as it does to be practical, flexible and responsive to change over time. Once again, however, the care economy lens enables us to see a number of important gaps:

1. The framework does not incorporate a gender analysis of programmes to assess the extent to which women – as unlinked family carers and/or as volunteers in formal CHBC programmes – have access to the resources (including respite) they need to undertake their caring tasks appropriately, and to assess whether the well-being of households in which these women live is being undermined.

2. Clearly, the resources necessary and needs of close kin to provide adequate care for their loved ones sick and dying of AIDS will be different from those of even the most rudimentary community-based voluntary care programmes. Nevertheless, almost all the CHBC policy frameworks aggregate these various types of care together under the CHBC rubric. According to WHO (2002a), for example, CHBC is defined as ‘any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities’. Gilks et al. (1998: 76) describe this domain in a similarly inclusive manner, as ‘any form of care given to sick people in their own homes. It can mean the things people might do to take care of themselves or the care given to them by the family or by health care workers’. Although the framework for

Community Home-Based Care in Resource-Limited Settings recognizes and includes the family as a key partner, the carer as beneficiary remains largely implicit. (3) The frameworks again fail in their attempts at holism by focusing solely on health care interventions, not taking into account other relevant sectors and actors within the community, whose resources could be usefully brought to bear in supporting families to care for those living with HIV and AIDS.

This section provided an overview of the health sector response to HIV/AIDS, and the development of the ‘care agenda’ at international level. While the ‘comprehensive care continuum’ and the care policy frameworks represent important advances, it is clear that more needs to be done at the level of international health policy to complete the ‘care agenda’. In the following section we suggest a possible way forward.

### An integrated management approach

As noted above, mitigating the impact of the pandemic on poor households in highly affected countries will be too much for any single sector or single type of intervention to undertake alone. Due largely to the current global political economy, national governments have increasingly coped by ‘downloading’ the burden of caring for those living with HIV and AIDS onto communities and individual households. As the public sector has retreated, ‘community-based care’ has become the de facto solution to the crisis of care, resulting in increased dependence on NGOs to set up programmes, even in the absence of evidenced-based good practices to model them on. Meanwhile, many communities and households in high prevalence areas are themselves increasingly unable to cope. As Steinberg et al. (2002: i) put it: ‘in already poor households, HIV/AIDS is the tipping point from poverty into destitution’. Clearly the strategy of downloading the burden of care on NGOs for CBHC is ‘ill-conceived’ (Quinlan and Desmond 2002).

Another important weakness of the policy response to HIV/AIDS care has been its exclusive focus on health sector interventions. Formal hospital-based care and CHBC are but two – albeit essential – strands of a truly comprehensive HIV and AIDS care agenda. Caring for a family member affected by HIV and AIDS requires ‘sanitation, clean water, and hygienic living conditions’ as well as provision for ‘economic and psychosocial factors which impact on healthy, risk-free living’ [http://www.hst.org.za/af-aids/msg01143.html]. Because care provides essential ‘public goods’, the needs of family carers include but extend well beyond the scope of most community home-based care programmes.

In seeking a broader response, Quinlan and Desmond (2002: 36) propose a ‘combined’ or ‘integrated’ approach, a process of providing care and support, which fosters the use of limited resources to maximum advantage. They propose that ‘community-based projects...combine health
and welfare interventions’ and suggest that non-governmental initiatives providing care to those living with HIV and AIDS and their families need to go hand in hand with state-sponsored efforts.

Yet, NGOs will not be able to advance such an agenda alone. Governments will need to do more, with implications for national budgets. Home-based care provision needs to be supported as a part of development expenditure, acknowledging the interface with poverty reduction, health, education and sustainable development (HelpAge International 2003). Although the response will cut across a range of sectors, it is likely that the health sector will need to take the lead in initiating and coordinating such a response. International donors, too, have a role to play, making way for real progress through a range of measures, including meeting their commitments to increasing development assistance to 0.7% of GNP, granting debt relief, and reforming their own macro-economic and trade policies to enable developing countries to achieve sustainable economic development.

Figure 4 applies the spirit of Quinlan and Desmond’s argument – that there is a need to combine state and community-based interventions – to the issue at the core of this paper, which is how best to link family caregivers to programmes to facilitate their care work. This figure shows an AIDS-affected household, which is well linked and well supported by health care programmes, within a backdrop of broader development activities and government involvement.

Conclusions and recommendations

This paper has reviewed the available literature addressing the domain of unlinked family care for HIV/AIDS, and found that this caring work, undertaken primarily by women, is largely taken for granted by both governmental and non-governmental efforts to mitigate the impact of the disease. Unlinked care occurs in households alongside the other caring work that women do to sustain their families, communities and nations; but as the epidemic progresses, the burden of caring for those living with HIV and AIDS can overtake and displace the other crucial work of the care economy, leaving households – and ultimately whole communities and nations – vulnerable to dissolution. Just as the fundamental importance of this caring work, and its many costs for the women who undertake it, continue to go unrecognized in national accounts, so too do they continue to go unrecognized and unaccounted for in the domain of national and international HIV/AIDS policy and programming.

The findings of this review highlight the need for a more coherent, expansive and inclusive ‘care agenda’, including the establishment of systems to help households and communities to provide care for those who are sick and dying from AIDS. Speaking at the African Development Forum in Addis Ababa in 2000, Peter Piot, the head of UNAIDS, echoed this finding, stating that the care agenda is ‘unfinished’, and advocating for a more multi-sectoral response (Piot 2000). Although many NGO and governmental programmes are in place, there is an urgent need for these programmes to more effectively integrate with each other and link up with the domain of family care. It is vital, however, that this process of integration incorporates a gender perspective: the issues of care, treatment and support must be seen through the eyes of the women who are most often responsible for providing them. Our review found that the myriad gender and age impacts of unlinked care continue to be downplayed in policies and programmes around HIV/AIDS care, and addressed in only a token fashion. This is the case despite widespread knowledge about the central role women of all ages play in the informal system of care, and a growing body of evidence on the particular needs and resources of older women and of children.

An important next step in the development of a more ‘linked up’ agenda will be making clear distinctions between care that is provided through formal structures (e.g. clinical and non-clinical care provided in the home by volunteer lay providers) and care provided in the home that is not supported through formal programmes (non-clinical care which is provided by family members, friends and neighbours). As has been shown here, the contributions of untrained, unrenumerated and unsupported family members to the care of people with HIV infection need to be seen as a distinct domain of care provision because the needs, resources and constraints of these providers are different, and because the mechanisms required for meeting those needs will be different.
This process should expand the scope of HIV/AIDS policy, incorporating a wider set of public and private sector domains, e.g., social protection, employment practices and policies, key public health infrastructure (water, sanitation, primary health care), agriculture, nutrition and housing. This expansion will have budgetary implications at international, national and local levels in terms of allocation of spending and revenues to include consideration of the needs of informal caregivers. As emphasized in a recent study on costing of the care economy, policy-makers and programmers must recognize that home-based care is not a cheap alternative to public health service provision (Columbia University 2004). Yet, costing this work is a necessary first step to recognizing, valuing and including unpaid HIV/AIDS care work in public health and other policy-making processes.

It is clear that the ‘care agenda’ is at long last advancing. An increasing number of voices are calling for more and better attention to the needs of those caring for people living with HIV/AIDS. It will be vital for these voices to be heard at national and international policy levels, and that action on expanding the ‘care agenda’ proceeds apace because of (if not despite) the increasing availability and accessibility of antiretroviral treatment in poorer countries.

Endnotes

1 According to Foster (2002b), households are often thought of as ‘a group of people, living together, who are usually economically interdependent’, a definition that implies a certain degree of stasis, as well as coherence and autonomy of one household vis à vis others. It is increasingly apparent, however, that households are actually more dynamic than this and are undergoing important (but still poorly understood) changes, particularly in highly HIV-affected communities (see also Barnett and Blaikie 1992). In this paper we use the terms ‘household’ and ‘family’ with full awareness of these dynamics, which lie at the heart of our concern with ‘care’.

2 For a useful review of methods for and policy impact of costing the care economy.


References


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