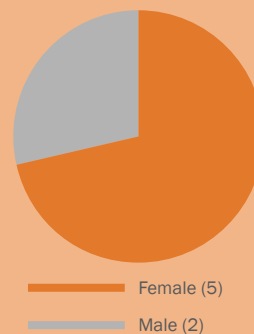


Policy Innovations *for* Transformative Change

Care Policies: Realizing their Transformative Potential (Chapter 3)



Demographic data about users who read and commented on this chapter:



As a learning organization that aims to be inclusive of diverse perspectives and responsive to our constituents, we held a consultation prior to the launch of our 2016 Flagship Report to make sure our work reflects the needs of our users.

On a scale from one (low) to five (high), users rated this chapter based on three criteria:

QUALITY
3,7

READABILITY
3,8

USEFULNESS
4,0



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Compendium of substantive feedback

Based on your knowledge and understanding, are we presenting an accurate picture of the topic?

Participant 1

No. Persons with disabilities are not simply "dependents". We are equal to care givers in every respect and holders of human rights too. Often our human rights are abused by those charged with caring for us, exactly because they are made to believe that we are "dependent" and not capable of making decisions about our lives ourselves. This may be in the family, in our own homes, or in mental health institutions where we are held and deprived of liberty and subjected to forced treatment without our consent, etc. The UN Convention on the Rights of Persons with Disabilities (CRPD) requires that States parties provide persons with disabilities with the support they need to exercise their legal capacity and right to make their own decisions. Any form of substitute decision-making by parents, guardians or carers must be abolished.

Participant 2

For the most part, yes. (1) The chapter would benefit a lot if somebody reviews it through a queer lens. Currently, the chapter understands gender narrowly as women. Older queer persons who stand outside family structures, trans-children who are abandoned, transsexuals who have undergone sex-reassignment surgery - all need care. The assumption that family is the basic unit of society resonates heavily in the chapter, yielding a heteronormative view of care. (2) Persons who stand outside family structures and who need care go beyond queer persons as well: e.g. in South Asia, widows, orphans, so-called beggars, slum dwellers, child migrant labourers and so on stand outside the Victorian family and need care. (3) Thanks for bringing out the link between unpaid domestic work and paid domestic work. I am afraid that the picture is much worse in a region like South Asia, known for its 'culture of servitude' (Raka Ray). The fact that practices like providing a 'servant quarter' (basically a shack) to paid domestic workers in lieu of wage amounts to nothing but modern slavery needs to be emphasised over and over again. The reason is that it is precisely the transfer of the burden of unpaid care work within upper middle class and upper class families to the paid care workers that contributes to this form of slavery. This is important, especially since the chapter boldly states that 'care policies are labour policies'. (4) There is a whole black box of sexual rights of the disabled which can considerably question our understanding of 'care'. See, for instance, Nucci (2011) (<http://philpapers.org/archive/DINSRA.pdf>). Should sexual pleasure to the severely disabled be publicly funded? This issue might take the chapter a bit too far, but it is useful in challenging a de-sexualised definition of care that the chapter currently seems to adopt.

Participant 5

Children's, especially girls', substantial, regular domestic and care work has not been mentioned in this chapter. There is now a significant body of literature documenting children and young people's care work globally.

I developed a typology of the different dimensions of children's care work globally (Evans, 2013, p.1989) based on my research with children caring for parents with HIV in Tanzania and the UK and with orphaned young people caring for siblings in child- and youth-headed households in Tanzania and Uganda. Several dimensions of children's care work above, which were verified through a participatory process with young people heading households in Tanzania and Uganda (Evans, 2012) are not covered in the definition of unpaid care and domestic work used in Box 3.1 - especially emotional support, self-care, income generation activities (to replace the loss of the parent's income/livelihood activities due to illness/death), household management and community engagement. More detail is needed in Box 3.1 about all the different elements that make up unpaid care and domestic work, as a means of recognising and re-valuing care that is often gendered and hidden within domestic spaces. Please cite the reference if using ideas from this typology.

I also suggest that 'girls and boys' are added to the sentence in this box: 'but the provision of care is unequally distributed not only between women and men, and girls and boys, but between the rich and poor...'

I have a related concern I have about the language of 'dependents' used in this chapter, particularly when referring to children, older/ elderly or disabled people. This constructs children, older people and disabled people as passive recipients of care and a 'care burden' rather than recognising that they may also actively provide care and support. Tronto's (2003) ethic of care perspective and the understanding of unpaid care and domestic work outlined in Box 3.1 highlights the fact that we all need to be cared for throughout the life course and there are often no fixed distinctions between the identities and roles of those who are 'care-givers' and 'care-receivers' (Tronto, 1993). My work has highlighted the fluidity of caring roles and the interdependent, mutual nature of care between children and parents living with HIV in Tanzania and the UK (Evans and Becker, 2009) and Namibia (Evans and Thomas, 2009), as well as the emotional tensions and resource constraints that undermine family members' ability to provide 'good care'.

The language of 'dependency' (eg. 'children and other dependents', p.4) also potentially conflicts with disability rights perspectives which for example could be seen as undermining disabled parents' rights and capabilities in caring for their children (Evans and Atim, 2011). This language implies that care is a 'burden' rather than drawing on a more holistic understanding that re-values care and is consistent with care ethics approaches.

I suggest that rather than referring to 'dependents', the phrase 'people with specific care needs' is used throughout the chapter and if needed, qualify with: 'people with specific care needs related to young or old age, ill health or disability' - as I have used in Evans (2010) and elsewhere. I also suggest that 'elderly' is replaced by 'older' people throughout.

Participant 6

We very much welcome the information provided in this chapter, which we consider as very useful. To be complete, data, evidence and policy recommendations should also be provided regarding children without or at risk of losing parental care. The necessity to reform child protection and care systems has already been recognised as key by several governments, the UN, the EU and other stakeholders to improve care policies and systems around the world.

Participant 7

In my view the chapter provides a very comprehensive analysis of unpaid care and domestic work and care policies in current development discourses and narrative. In some occasions, the information and analysis are overwhelmed. Thus, it distract the reader to focus on the key issue: whether the design of care policies; or the gender lens to care; or care in the 2030 development agenda, or all together at once etc. In addition, the use of the concept "transformative" as an attribute to care policies is a bit abstract. During the last years, the development narrative and discourse have used too often the concept of "transformative" to refer a very different range of policy issues and, concepts. It seems anything to be named in policy development has to be somehow "transformative". In my view "transformative" is becoming a kind of a buzzword in development policy and practice. It does not have either any conceptual framework to really express what do we really mean by "transformative". In this sense, I would suggest to speak about substantive equality and, the potential that care policies have to achieve substantive equality. As you know, substantive equality has a robust body of research, the concept has been very well described by scholars and, it is endorsed by several key international actors. In addition, substantive equality means exactly that "transformation" in terms of structures and social and economic institutions.

Are the policy conclusions and recommendations useful?

Participant 1

Not to persons with disabilities directly, except the paragraph on lack of access to health care services, which however needs more explanation, and the remark on basic income security. This should however be extended to include personal assistance payments to the person with disabilities themselves, so they can hire the care they need and are the employer in such a relationship. The conclusions and recommendations may be more useful to family members who provide unpaid care.

Participant 2

It would be useful to know how the developing countries can generate additional revenue to finance care policies. This is a question under the general rubric of financing social policies.

Participant 4

They provide a big picture... It's important to focus on the poorer countries...

Participant 5

Yes, but see suggested edits to chapter:

p.6 'provision of infrastructure that reduces women's and children's workloads, such as communal wells and piped water' - children are often responsible for water collection.

p.6 an array of income security and social protection policies...

p.9 section on 'care services cater for dependent populations' - suggest heading is changed to 'cater for people with specific care needs'. This section discusses childcare and care for older people, but only contains a short paragraph on healthcare for disabled people and does not discuss access to social care/formal care support. It does not mention HIV care and support - care for people living with HIV and for orphaned and vulnerable children or care for people affected by health emergencies such as Ebola.

p.9 fetching water, which is a time-consuming activity typically done by women and children.

p.10 'Infrastructure deficits....make it harder for care-givers and care-receivers to access care services'

p.10 section on social protection policies and discussion of cash transfer programmes - include examples here of cash transfers for families affected by HIV? there is extensive evidence about the impacts of these in Africa

p.14 fetching water is generally women's and children's work....

p.19 reference 109 - relating to caregivers and care receivers' potentially conflicting rights - could include here reference: Evans, R. and Atim, A. (2011)

p.21 section on how care is framed varies considerably - there is no discussion here about care in relation to HIV in Africa? See Evans and Atim (2011) for discussion of PLHIV's advocacy and contribution to the global HIV care agenda, as well as challenges in influencing global and national policies on the care and support of PLHIV. As we discuss in Evans and Atim (2015), a global Caregivers Action Network was established by key stakeholders in 2009 and Agnes Atim established the Caregivers Action Network Africa at the 2012 International AIDS Conference in Washington DC in order to further develop policy, research and caregivers' mobilization in Africa.

p.22 'Where the public sector is absent...' include here example of PLHIV taking on roles as caregivers and providing healthcare in northern Uganda (Evans and Atim, 2011, 2015). See also Q.3 below.

p.22 Care is moving up the agendas of labour and care receivers' rights movements - include here also advocacy by PLHIV on HIV care and support, not only advocacy by paid care workers or by care receivers. See suggestion above for p.21 - mention global Caregivers Action Network and the Africa branch founded?

p.24 discussion of broad alliances - could also include example of PLHIV and disabled people lobbying together - see Evans and Atim, 2011.

p.25 time-use data - there is also a need for gender disaggregated time-use data on children's care work to be collected. See Evans, 2012 for participatory time-use exercise conducted with young people heading households.

p.25 'care policies can contribute to gender equality and children's rights, or be detrimental to them.'

p.25 SDG target 5.4 lists.....ways to recognise women's and girls' unpaid care and domestic work.

p.26 Transformative care policies are more likely to emerge when:

- channels...trade unions and children's, disabled people's, people living with HIV and older people's rights organisations

Participant 6

Yes, we welcome the strong emphasis on a holistic and rights based approach and decent work for care workers.

Participant 7

In my view, the report provides interesting conclusions but I do not necessarily read those conclusions in terms of policy recommendations. If possible, I would suggest to elaborate more on policy recommendations and, to provide actors and institutions responsible to take forward those recommendations. It would be very useful specific policy recommendation to leverage up the care agenda and care policies in less developing countries to avoid a "pick and choose" target in the 2030 Development Agenda.

Are we missing something? (Examples, data, etc.)

Participant 1

Care policies need to be based on the human rights of the persons that are the recipients of such care. Not all "care" is good or welcome. It should in particular be stressed that all care policies aimed at persons with disabilities need to be developed in consultation and collaboration with persons with disabilities and their representative organizations, as required by the CRPD. Nothing About Us, Without Us.

Participant 2

The concept of 'time poverty' is mentioned. It will be useful to have data on the subject - not only for the time poverty experienced by care givers within families, but also that experienced by (under/non) paid domestic workers.

Participant 3

Impact of cultural norms?

Participant 4

The local development approach....Please see my chapter "Redistributing care: towards a public policy nexus / Nathalie Lamaute-Brisson .-- Chapter II" in REDISTRIBUTING CARE. THE POLICY CHALLENGE (ECLAC, 2013), <http://www.cepal.org/en/publications/redistributing-care-policy-challenge>.

Participant 5

There is currently no discussion of how people living with HIV have helped to shape global HIV care and support policies and are involved in healthcare delivery in northern Uganda (Evans and Atim, 2011; 2015) in addition to providing home-based care and peer support globally. Such interdependent caring relations blur conventional boundaries between 'care-givers' and 'care-recipients', and constructions of 'service users' as dependent, passive recipients of healthcare (Evans and Atim, 2015). Our chapter highlights the gendered nature of PLHIV's voluntary roles in healthcare delivery in northern Uganda. This example could be included on p16 when discussing care workers and the fact that they are underpaid and overworked.

References cited above:

- Evans, R. (2013) 'Children as caregivers', in A. Ben-Arieh, F. Casas, I. Frones and J. E. Korbin (Eds.) Handbook of Child Wellbeing, Heidelberg: Springer, pp.1893-1916.
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Other references on children's care work and young caregiving globally :

- Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family: Research and policy on 'young carers' in the UK, Australia, the USA and Sub-Saharan Africa. *Global Social Policy*, 7(1), 23–50.
- Bray, R. (2009). A literature review on child carers in Angola, Nigeria, Uganda and Zimbabwe. Unpublished report. London: Save the Children UK.
- Evans, R. and Skovdal, M. (2015) 'Defining children's rights to work and care in Sub-Saharan Africa: tensions and challenges in policy and practice' in Kallio, K. P. and Mills, S. (2015) (eds.) *Politics, Citizenship and Rights*, Vol. 7 of Skelton, T. (ed.) *Geographies of Children and Young People*. Springer: Singapore.
- Evans, R. (2011). "We are managing our own lives. . .": Life transitions and care in sibling-headed households affected by AIDS in Tanzania and Uganda'. *Area*, 43(4), 384–396.
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- Skovdal, M., Ogutu, V., Aoro, C., & Cambell, C. (2009). Young carers as social actors: Coping strategies of children caring for ailing or ageing guardian in western Kenya. *Social Science & Medicine*, 69, 587–595

Participant 6

A reference to the impact of transformative care policies on children at risk of losing parental care or without parental care is missing. In many countries across the world children are still separated from their families because of poverty. Disadvantaged families cannot take care of their children because they cannot access quality child care services in their community and cannot combine their care duties with employment. In line with the UNCRC, transformative care policies should take a holistic approach which includes adequate measures to avoid family separation because of poverty. Reference should also be made to the provision of quality alternative care for children who have lost parental care. A range of family-based and family-like care solutions should be available in the community to meet the individual needs and rights of these children. To prevent an institutional care culture, care professionals should be trained to apply a child rights based approach in their daily work.

Participant 7

The chapter refers too often to human rights language. It speaks about right-based approaches and, the rights of caregivers and care receivers. However, the chapter does not address any information and/or reference to the normative international human rights framework.

The CEDAW, despite its focus on discrimination against women and substantive equality, has remained relatively silent on the topic. International human rights treaties follow the formal equality model in regards unpaid/paid work. The CESCR, in two general comments on the right to work (2006) and the right to social security (2007), fails to recognise women's unpaid work and its remunerative value. The ILO's Social Protection Floor Recommendation also fails to recognise women's unpaid work – it sees social security as a worker's right rather than a human right. In addition, CEDAW in Article 11 concerning the right to work requires States to ensure the "same" right to women and men in relation to work, equal opportunities, and equal remuneration without tackling the constraints of unpaid care work for accessing the labour market.

Now only recently has the CEDAW drafted a general recommendation on rural women in which care and domestic work are addressed in a more holistic way as a means of achieving de facto equality for rural women. The CEDAW, as a women's focus Covenant, should take steps to clearly put forward the connections between substantive equality and women's unpaid care and domestic work. A good point of departure could be the recent general recommendation on rural women in which the CEDAW Committee incorporates a progressive understanding of care together with a robust gender analysis about the impact of care work on the lives of rural women and girls. However, the scope cannot remain limited to "rural women" because unpaid care work impacts on the lives of all women independently of their economic status, education, and geographical setting. In my view, a more robust analysis of the current normative framework is needed to inform care policies. At the moment, there is a gap in this normative framework in terms of care, women's unpaid care and domestic work.

Finally, I would like to congratulate UNRISD for all the research work conducted in this important subject during years and, to have included the issue of care policies in this important report as a key policy issue.