Submission

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Discussion Paper:
Designing the new integrated carer support service

Kathryn Knight, PhD

Email: kathryn.knight7@gmail.com

Blog: women carers: rights and wrongs
https://carerrights.wordpress.com

Introduction

The need for reform to the delivery of services and other supports to the carers of Australia is incontestable, and the discussion paper outlines many of the reasons why this initiative is necessary. While the proposed model addresses key points in terms of integrating service delivery system that is currently fragmented and difficult to navigate, it neglects to engage with several critical issues that impact the lives of carers. These issues have important implications for the responsiveness of any future model, and its application as a sustainable, progressive service delivery system that will meet the needs and expectations of carers into the future.

In this submission, I address the following as fundamental to the realisation of transformative outcomes for carers:

- recognition of the gendered nature of caring
- the need for a human rights approach to unpaid caregiving as a social institution
- acknowledgement of the diverse nature of caregiving scenarios across the life cycle.

My approach in this submission arises from my personal situation as the mother and primary carer of an adult daughter with a severe disability, and is informed by my doctoral research work in the areas of disability, motherhood and caregiving.

1. The gendered nature of caregiving

‘Caring is not, of course, an exclusively female activity – it is just that the status of caring has been engendered by the fact that it is women who provide the bulk of it’ (Clements 2013). A significant body of research and analysis provides evidence that the load of unpaid caregiving in Australia falls predominantly on women. According to a Human Rights Commission report, ‘Women comprise 92 per cent of primary carers for children with disability, 70 per cent of the primary carers for parents, and around half (52 per cent) of the primary carers for partners’ (2013, 2). Carers NSW research confirms these statistics, reporting that ‘there are more female than male carers across all age groups up to 75 years of age, at which point more men than women are carers' (Vallentine 2015).

In spite of this clear evidence, no mention of the gendered nature of unpaid caring appears in the draft Service Concept, nor in any other carer-related government policy documents. This omission serves the women carers of this country poorly because, as a critical matter that is nevertheless rendered unspoken, it normalises the unpaid caregiving obligations faced by women.

Women predominate as carers in all caring scenarios except as partner carers or young carers (who are female and male in roughly similar numbers), whether mothers of children with disabilities, mothers of adult sons and daughters with disabilities (often sole carers), daughters of frail aged people, or adult sibling carers. The physical and mental health impacts, as well as the social and long-term financial costs and disadvantages that necessarily accompany the role of unpaid carer have been well documented (e.g. Cummings 2015), and these are compounded for women carers who already face systemic gender disadvantage in areas such as workplace equality, pay rates, and accumulation of superannuation.

That a significant initiative such as the draft Service Concept fails to acknowledge and address this fundamental characteristic of unpaid caregiving in Australia is worrying, if not alarming. Colloquially speaking, this is 'the elephant in the room'. By ignoring gender issues, policymakers risk alienating those to whom services are directed: women carers. Policymakers also jeopardise the sustainability of their programs, because the new generation of young, educated and aspirational women will be more resistant than their older counterparts to the social and moral obligations that compel them into roles as unpaid carers.

It's now time put gender onto the caring policy agenda.

2. The need for a human rights approach

The aims of the draft Service Concept can be summarised as seeking to improve outcomes for carers, and to provide supports that will ‘help carers sustain the caring role and avoid a crisis that might adversely affect or end it’ (page 10). Underlying these aims is an economic imperative, given that ‘the replacement value of these unpaid care hours would be $60.3 billion’ (page 8). The sustainability of the caring relationship, and the maintenance of the individual in the role of unpaid carer are hence focal points of the draft Service Concept.

Essential to the realisation of these aims is carers’ identification with the socially constructed identity of the ‘carer’, or what Clements (2013) describes as ‘the formalised public status of being a carer: one that transcends the private and the personal’ (2013). The strategies outlined in the Service Concept document support this position, as they are predicated on carers’ compliance with this socially determined carer role.

Unpaid caring is seldom an activity taken up by choice. Rather, the carer is recruited through a complex interaction of moral, emotional and relational expectations that bring with them social marginalisation, among other disadvantages. The impacts of this marginalisation are evidenced in, for example, the findings of the 2015 Australian Unity Wellbeing Index, which revealed that unpaid carers have the lowest wellbeing of any group in the population, including the unemployed.

In contrast, a human rights approach in carer policy would foreground not so much carers’ compliance with their co-option into the carer role as their capacity as citizens to participate in economic and social life on a par with their non-carer peers. Various commentators have raised human rights issues in relation to unpaid caregivers (Fineman 2005, Kittay 1999, Clements 2013). Clements compares the sense of social exclusion faced by carers with that of people with disabilities, but while people with disabilities are seen as ‘rights holders’, carers are yet to receive such recognition. Instead, he writes, ‘The support carers receive is still viewed as evidence of the state’s beneficence rather than as compensation for the discrimination they experience from the non-carer majority’ (Clements 2013).

A human rights approach would involve strategies that promote participation in the society at large, rather than those that focus on identification with the marginalised carer community. Options include rebates for working carers to assist with the high costs of out-sourcing care so that carers can participate in the economic life of the community; increased respite provisions (which carers identify as high priority); support for workplace training and education for carers who have been excluded from the workforce; and support for carers to participate in social activities outside the carer role. These strategies would assist in breaking down what is essentially a ghettoisation of carers.

Such an approach requires a paradigmatic shift in thinking, but one which will promote the sustainability of caregiving as a socially valued role into the future.

3. Acknowledgement of the diverse nature of caregiving scenarios and changing needs across the life cycle

The word ‘carer’ is used in the Service Concept document as an umbrella term that encompasses a broad range of unpaid caregiving scenarios, including children and young people who care for adults; parents and kinship carers of young and school-aged children with disabilities; parent carers of adults with disabilities; partner carers; and carers of frail aged people and people with dementia. This broad group of caregivers ranges in age from children to people aged 75 years and above.

The proposed Service Concept applies the same model of service delivery across these diverse scenarios, with the assumption that these groups of people who experience very different intensities of caring obligations and who are at different stages of the lifecycle require the same set of support needs. The special needs of groups that experience compounded disadvantage – young carers, ATSI carers, carers from CALD, and LGBTI carers – are rightly considered, but no further segmentation of the very broad spectrum of carers is explicitly addressed.

As the Service Concept document reports, care hours are not evenly distributed, with 19% of carers undertaking 54% the caring load (page 8). The Carers NSW 2014 Carer Survey revealed that the negative impact of caring was greatest amongst those who provided more than 70 hours of care per week, were aged between 45 and 64 years, and had been providing this level of care for over 15 years (typically women caring long-term for a son or daughter with disability). In contrast, the Service Concept document reports that 'about one third of carers report neither strain nor negative health effects' (page 8). And yet the proposed model does not differentiate not address the specific needs of this group of high intensity caregivers from those lower demands. This group of intensive caregivers requires particular and targeted consideration.

The Service Concept document also neglects to address explicitly the challenges faced by carers at different life stages, and accordingly the types of services that are most appropriate. For example, carers of young children with disabilities have a very different set of needs (including peer support and mentoring) from women carers of adult children with disabilities (who may require practical support to participate in the workforce) or older carers of partners with dementia (who may be more likely to require personal assistance and support for social participation). In order to engage clients positively, the proposed model must attend to these critical issues around life stage, and instil confidence in carers that their particular needs are recognised and will be addressed.

Conclusion

The proposed new service model takes up the challenge of better integrating a currently fragmentary service delivery system. In so doing, however, it misses an opportunity to move forward into rethinking the carer role and carer needs in a rapidly changing social environment. In this submission, I have addressed three issues that I believe have particular relevance for carers now and into the future:

- the predominance of women as unpaid carers, and the lack of acknowledgement of this fact in policy
- the emphasis on sustaining the care relationship, often as an economic imperative, rather than addressing the citizenship rights of carers to engage in full social and economic participation
- the importance of responding explicitly to the needs of those who provide intensive caregiving, and to the changing needs of carers across the lifespan.

References

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