



# Bounded choices: The problematisation of longterm care for people ageing with an intellectual disability in rural communities



Lia Bryant\*, Bridget Garnham

Centre for Social Change, School of Psychology, Social Work & Social Policy, Division of Education, Arts & Social Sciences, University of South Australia, Adelaide, South Australia, Australia

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## ABSTRACT

The increasing longevity of people with an intellectual disability and concurrent ageing with their older parental carers is generating a problematisation of longterm social care in the community. In rural communities this problematisation is complicated by spacial distribution and paucity of specialist disability and aged care services to cater to the emerging needs of these families. In-depth interviews with six families in rural South Australia were conducted to explore their experiences of caring in the community and future post-parental care plan for their son/daughter with an intellectual disability. The data reveal how the gendered nature of care installs moral responsibility for care through maternal subjectivity and problematizes relinquishing that care. The relinquishing of care was also problematised by a delimited discourse on care transition with a foundation in uncertain futures and bounded choices for longterm post-parental care. Powerful normative constructions of the 'good mother' are therefore at the heart of the 'carescape' for intellectual disability and shape intersubjective relations between mothers and their sons/daughters, neoliberal community care policy and practices and emotions associated with caring. The ethic of care normalised in the context of this carescape legitimates the State's limited provision of statutory services and supports for carers and people with disabilities. However, the increasing life-expectancy of people with intellectual disability and the age-related needs of their parental caregivers is problematizing this social service lacuna. The absence of clearly demarcated and suitable pathways for future care transition is an everyday lived uncertainty for older rural carers, subject to the agency of others and a concern that their son/daughter will enter into less desirable forms of care. Delimited agency and opportunity for those who give and receive care requires problematisation of the political, cultural and moral discourses through which longterm social care in the community is constituted.

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## 1. Introduction

Internationally, the increased longevity and ageing of people with intellectual disabilities is posing a significant multi-faceted challenge to families, social research, government policy and organisational policy and practice in the aged care and disability service sectors (Bigby, 2010; Doody et al., 2013a,b; Wark, 2014). Uncharted intersections between disability and ageing are requiring new knowledge to inform health and social care practice and are challenging existing models of disability support (Doody et al., 2013a,b; Wark, 2014). In addition, since the majority of

people with an intellectual disability live in the family home and are primarily cared for by a parent, concurrent issues of ageing intertwine, as care-giver and care-recipient grow older together, to complicate the caring relationship (Pruchno, 2003; Walker and Ward, 2013).

The issues that are emerging from the increasing life expectancy of people with intellectual disabilities are driving a problematisation of existing structures and practices of longterm social care in the community. As Rose (1996: 26) explains, problematization refers to 'practices where conduct has become problematic to others or oneself' and the attempts to 'render these problems intelligible and, at the same time, manageable'. One of the key points of problematisation in the research literature has focused on the ageing of older parent-caregivers and capacity to continue providing care (Chou, Fu, Lin and Lee, 2011; Chou, Pu, Fu and Kröger, 2010; Cuskelly, 2006; Greenberg and Kim, 1997; Llewellyn et al.,

\* Corresponding author.

E-mail addresses: [Lia.Bryant@unisa.edu.au](mailto:Lia.Bryant@unisa.edu.au) (L. Bryant), [Bridget.Garnham@unisa.edu.au](mailto:Bridget.Garnham@unisa.edu.au) (B. Garnham).

2010; Seltzer et al., 2011; Taggart et al., 2012). Another central point of problematisation is that people with intellectual disabilities being cared for in the community are increasingly expected to outlive their parent caregiver (Bigby, 1998, 2000). A mid-life transition to alternative care, and often, residential arrangements when older parents are no longer capable of providing everyday care due to death or incapacity is thus becoming an expectation for this population (Bigby, 2000). The social service literature responding to these issues has therefore focused on client needs, sources of support and planning for and experiences of post-parental care transitions for people ageing with intellectual disabilities (Bigby, 1998, 2000; Bowey and McGlaughlin, 2007; Burke et al., 2015; Dew et al., 2004; Taggart et al., 2012; Walker and Ward, 2013).

Whilst much of the Australian literature, like that of other neoliberal welfare states, is urban-centric, a small body of rural research on social care issues at the interface of ageing and intellectual disability is emerging (Eley et al., 2009; Wark et al., 2013, 2014). This is an important focus since 'care is structured and practiced in spacial ways' through 'interrelationships between people, places and care' (Miligan, 2014: 1). The expectation of a transition from normative arrangements of primary parental care for people with intellectual disability illuminates and problematizes possible configurations of informal and formal care. However, geographical location significantly influences the availability, range and specialisation of formal disability services and supports. This suggests that the challenges posed by ageing and intellectual disability for families and service providers in rural communities will be amplified (Wark et al., 2014). Indeed, research findings indicate substantial unmet need, particularly in terms of residential support for people ageing with an intellectual disability and their parental-caregivers in rural places (Eley et al., 2009) and some of the issues and barriers for community care providers attempting to service this population (Wark, 2014; Wark et al., 2013).

Much of the social care literature focuses on psychosocial dimensions that include the everyday practice of care, the needs of those giving and receiving care, the impacts of caring on the individual and their circumstances and social support for the care recipient or caregiving relationship by organisations and services. This approach is providing important descriptive evidence of the emerging issues at the interface of ageing and intellectual disability (e.g. Cuskelly, 2006; Llewellyn et al., 2010; McCausland et al., 2010; Taggart et al., 2012). However, the way in which care emerges at the level of everyday practice is also conditioned by broader 'care-scapes' (Bowby et al., 2010), the socio-political, cultural and moral discursive frameworks situated within history and geography (Phillips, 2007). As Kittay et al. (2005: 444) argue, 'norms surrounding both the giving and receiving of care, whilst dictated in part by the nature of human need, [are] also conditioned by cultural and ethical understandings and by economic and political circumstances' (Kittay et al., 2005: 443). This means that care needs to be examined at not only the level of everyday practice, but as contextualised by social structures and relations of power (Lynch, 2014; Rummery and Fine, 2012). These contexts include the socio-political, cultural and moral discourses through which social care is constituted. In addition, urban-centric constructions of care provide a specific socio-spatial politics of care and particular geographically situated configurations of care. These discourses, contexts and configurations of care do not remain static, but rather constantly evolve in response to social problematisation and can be challenged to provide new ways of thinking about, and thus engaging in, longterm social care. This makes 'questions concerning the giving and receiving of dependency care a matter of social, moral and political import' (Kittay et al., 2005: 445). In this paper we argue that the problematisation of the point of transition into

post-parental care offers a site for critically examining the contexts and conditions shaping longterm social care for people with an intellectual disability in the community. This type of examination will be critical to informing the targets of the social reform needed to provide quality care, choice and opportunity for people ageing with intellectual disabilities. To begin this critical intervention, this article draws on exploratory research with older parent-caregivers of people ageing with an intellectual disability in rural communities in order to examine how care is constituted in ways that render relinquishing care and transition to post-parental care problematic.

## 2. Caring is complex

As an unassuming feature of everyday life, care often only becomes visible at a point at which it can no longer be taken for granted. Contemporary social issues connected to ageing, disability and raising children that trouble the interface between the 'private' domain of the family and 'public' domains of social policy, work and the economy provide a locus for current social problematisations of care. Conceptions of care as a complex, multifaceted and situated construct emerge from this problematisation, shaped by the discourses of academic disciplines, social movements, social policy and organisations. At the level of everyday practice, this problematisation has produced conceptions of care that acknowledge the 'complexity of care' (Rummery and Fine, 2012: 329). Care is constituted at a deeply gendered nexus between affective social relations, the political economy and ethics (Lynch, 2014). Western neoliberal political discourses constitute the autonomous and independent citizen normative and render human interdependencies problematic. This means, as Kittay et al. (2005: 457) argues, that 'Dependency concerns are largely a matter of structural inequality'. In addition, the Cartesian rationality underpinning western political discourses devalues emotions and affective relations and operates to marginalise care from the public domain of politics and the economy (Lynch, 2014). Governmental ideologies therefore install social responsibility for care within the affective relations provided by the privatized sphere of the family and principally the ethical responsibility of women (Bowby et al., 2010; Lynch, 2014).

Caring is gendered through discourses that constitute the private labour of caring as the domain of women and emotional caring as integral to feminine subjectivities (Hollway, 2006; Phillips, 2007). In particular, the responsibility for caring and capacity to provide care are deeply enmeshed with maternal subjectivities (Hollway, 2006; Phillips, 2007). As Longhurst (2008) has argued, meanings about mothering are multiple, shifting and socially constituted within specific times and cultures. Despite heterogeneous experiences of mothering, hegemonic discourses that mark and shape the mothering body as naturally nurturing and caregiving remain powerful in western economies (Hollway, 1999). Through the performance of care practices, maternal discourses become embodied and constitute the caring subject (Skeggs, 1997). Everyday practices of mothering involve practices of care that encompass responsibilities and practical tasks in conjunction with emotions associated with caring like love and tenderness. What this means is that the 'caring subject is constructed by the conflation of caring *for* with caring *about*, in which the practices of caring become inseparable from the personal dispositions' (Skeggs, 1997: 56). These embodied practices and affect provide the basis for a dialogic production whereby the caring self is constituted in relation to the care recipient. Hence, maternal subjectivities are inherently intersubjective (Bowby et al., 2010) shaped through the provision of care in response to the dependency needs of one's child. Meeting the needs of one's child thus provides a foundation for moral constructions of the 'good' mother. Normative

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