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Policy, plans and pathways: the 'crisis' transition to post-parental care for people ageing with intellectual disabilities in rural Australian carescapes

BRIDGET GARNHAM*, LIA BRYANT*, PAUL RAMCHARAN†,
NILAN YU* and VALERIE ADAMS*

ABSTRACT
The concurrent ageing of parental care-givers and people with intellectual disabilities is driving academic and social welfare concern for a post-parental care 'crisis'. The 'crisis' typically pertains to a transition from primary care in the family home precipitated by the death or incapacity of older parents without a pre-planned pathway to post-parental care. This crisis is amplified in rural communities given low service engagement with families and a deficit of disability-supported accommodation and services. Academics, service providers and policy makers have responded through a problematisation of post-parental care planning. This focus continues to normalise informal care, burdens families with responsibility for planning, and diverts attention from structural deficits in the socio-political carescape. This paper attends to the Australian policy landscape in which long-term care-giving for families living with intellectual disability is enmeshed. It contends that the dyadic and didactic model of informal long-term care has profound implications for social service support and post-parental care planning. Problematisation of carers' 'need' to relinquish primary care and for people with intellectual disabilities to transition to independent and supported living is necessary to unsettle the dominant policy and service discourse around the provision of services to sustain informal care-giving. Innovation is then needed to forge pathways of support for families in rural communities planning on continuing, transitioning and transforming care arrangements across the lifespan.

KEY WORDS – post-parental care, ageing and intellectual disability, rural, informal care, older carers, Australia.

Introduction

The population ageing of people with intellectual disabilities and the corresponding 'problem' of transition to post-parental care and predicted service

* Centre for Social Change, University of South Australia, Adelaide, Australia.
† Future Social Service Institute, RMIT, Melbourne, Australia.

system strain are emerging as international issues affecting many advanced democracies including the United Kingdom, Australia, the United States of America (USA) and Scandinavia (Bigby 2000; Hewitt *et al.* 2010; Ng, Sandberg and Ahlström 2015; Taggart *et al.* 2012). For a large proportion of people with intellectual disability being cared for in the family home, a mid-life transition to out-of-home and post-parental care has become a normalised 'crisis'. The crisis is generally occasioned by the death or incapacity of older parental care-givers to continue primary care in the home and the absence of a clear pre-planned pathway to alternative residential and other care arrangements (Bigby 1996, 2008; Bigby, Ozanne and Gordon 2002). An assumption in much of the planning discourse is that the family will provide the locus for primary care, only to terminate upon the death or incapacity of parents – as opposed to an earlier relinquishing of care or planned transition to disability-supported and independent living. This means that even within the discourse of pre-planning, the 'crisis' of transition is reinstated. In Australia, this is particularly so in rural communities where histories of care across the lifespan are characterised by substantial unmet need for residential disability support, and particular issues and challenges for social service providers in rural community care (Bryant and Garnham 2016; Eley *et al.* 2009*a*, 2009*b*; Hussain *et al.* 2014; Walker and Ward 2013; Wark, Hussain and Edwards 2014). For many families, the inevitability of the post-parental care transition is forestalled as a future event clouded in uncertainty, as older parental carers strive to continue primary care in the home for '*as long as possible*' (Eley *et al.* 2009*a*: 3, emphasis added; *see also* Bryant and Garnham 2016; Muraver 2001; Taggart *et al.* 2012). Indeed, evidence that older parental carers will neglect and sacrifice their own health and support needs despite increasing frailty and exhaustion (*e.g.* Bryant and Garnham 2016; Cairns *et al.* 2013) reveals the power of the moral discourse that primary care should be sustained for the duration of their lives. Unpacking this normative discourse in relation to its social, political and ethical surfaces of emergence will provide crucial insights into the formation of the current post-parental care crisis.

This paper provides a fresh perspective to the 'problem' of post-parental care planning in Australia by attending to the broader policy landscape in which long-term care-giving for families living with intellectual disability are enmeshed. As Bryant and Garnham (2016: 261) argue, in advanced democracies the 'political economy installs long-term social care into the affective relations provided by the family through an ethic of care connected to maternal subjectivities'. This gendering of long-term social care is evidenced by the substantial proportion of mothers, including sole mothers, who provide primary care in the family household for people with intellectual disability (Australian Bureau of Statistics 2014; Australian

Institute of Health and Welfare 2016; Bryant and Garnham 2016; Irazabal, Pastor and Molina 2016; Qu, Edwards and Gray 2012). The academic literature acknowledges the reciprocity, interdependence and intersubjective nature of care dyads constituted through relations of care-giving and care receipt (Bowlby *et al.* 2010; Kittay, Jennings and Wasunna 2005; Phillips 2007; Rummery and Fine 2012). However, social policy constructs the care dyad through individual 'needs' of care-giver and care recipient and tends to support the care-giver insofar as sustaining the relationship of informal care so that the needs of the care recipient are met (Heaton 1999). The economic rationalist ideology that underpins the vested interest of the State in the care dyad is generally obscured through normalised discourses of preference, choice and family as a natural locus of care (Twigg and Atkin 1994). Buttressed by 'bounded choices' for alternative social care arrangements, an ethic of care-giving is enacted that renders relinquishing or transitioning care arrangements morally problematic for older parental carers (Bryant and Garnham 2016; Irazabal, Pastor and Molina 2016).

The way in which care emerges at the level of everyday practice is conditioned by broader 'carescapes' (Bowlby *et al.* 2010), the socio-political, cultural and moral discursive frameworks situated within history and geography (Phillips 2007). Rural 'carescapes' emerge from scarcity and geographic dispersion of formal disability and aged-care services and supports and normative rural cultures of care-giving. These carescapes are often problematised in the literature in terms of the deficits presented by a rural 'disability desert' (Pini, Philo and Chouinard 2017: 225). Such a perspective rightfully points to the under-resourcing of many rural places in terms of professional and specialist services and the attendant social isolation and deprivation experienced by families that ensures self-sufficiency emerges as the only reasonable life strategy (Bryant and Garnham 2016; Llewellyn *et al.* 2010). In the literature on ageing and intellectual disability, however, this broader carescape, in which ageing and disability are experienced, often becomes erased. A central focus of this literature and social policy targets older parental care-givers in terms of responsibility for preparing adequate plans for transition of their ageing son or daughter with an intellectual disability to post-parental care arrangements (Bibby 2013; Bigby 2000; Bowey and Mcglaughlin 2007; Heller, Caldwell and Factor 2005; Senate Community Affairs Reference Committee 2011; Taggart *et al.* 2012). Review of the historical trajectory of this literature, however, consistently reveals a disinclination among ageing parental care-givers to formally plan for this future transition and a normalised 'crisis' of transition to post-parental care (Bigby, Ozanne and Gordon 2002; Bowey and Mcglaughlin 2007; Brennan *et al.* 2016; Senate Community Affairs Reference Committee 2011; Taggart *et al.* 2012). Taken together, these points suggest a stalling point for academic and social welfare practice, where the field remains fixated due to an incapacity to either resolve the 'problem' or comprehend the impasse.

This paper contends that when considered within the current socio-political context, the problem of transition to post-parental care in Australia is an inevitable outcome of 'community care' policy frameworks that install social care into a care dyad with a finite trajectory that terminates with the death of the care-giver. The ensuing 'crisis' therefore arises, not simply as a result of families' failure to provide adequate plans for post-parental care, but as a socio-political dead end in long-term community care. Rather than problematise 'post-parental care planning', innovation in policy and service sectors is needed to forge pathways of support for families in rural communities continuing, transitioning and transforming care arrangements across the lifespan.

Dyadic and didactic care in the community

In advanced democracies, the contemporary long-term social carescape is premised on a policy terrain designed to facilitate greater proportions of older people and those with disabilities to live in the community with the support of decentralised health, aged and social care services (Beadle-Brown, Mansell and Kozma 2007; Wiesel and Bigby 2015). The community care policy reforms that occurred through the 1970s, 1980s and 1990s were infused with neoliberal governmental notions of 'choice' concerning where to live and with what supports (Foster *et al.* 2012; Purcal, Fisher and Laragy 2014). Current social care policy reforms in Australia in ageing (Consumer Directed Care) and disability (National Disability Insurance Scheme; NDIS) are implementing individually funded budgets connected to care plans for the purchase of necessary services and supports from the care 'marketplace'. These current reforms are expected to provide the levers to further dissolve the service-centric landscape and provide greater 'personalisation' of care (Laragy *et al.* 2015).

Individual 'needs' provide the basis for the personalisation approach. However, rather than an individual quality, 'need' is socially constructed and 'molded by powerful and hegemonic interests, identities, and ideologies that arise in various parts of the system' (Browne 2010: 586). In relation to care that meets identified and assessed 'needs', this means that the 'principles of care are in many cases increasingly subordinated to commercial, political and organizational imperatives in what are today largely understood as "service industries"' (Browne 2010: 586). In practice, the 'needs' of service users in the disability and aged-care sectors have been undermined by chronic funding shortages, cultures and practices of rationing, service fragmentation and inflexibility, workforce issues and inefficiencies (Wiesel and Habibis 2015). As research and stakeholder consultation consistently reveals, people living with disability or providing care for a person with a disability experience 'their lives as a constant struggle – for support, for resources, for basic necessities, for recognition' (Miller and Hayward 2017: 134).

Long-term care in Australia is currently constituted in relation to a mixed economy of 'informal' or non-paid family care with 'formal' care services provided through for-profit and not-for-profit social care organisations (Heaton 1999). 'Informal' primary care-givers largely provide everyday care and support within the family home, including assistance with everyday living and personal care, managing health and psychological conditions, decision-making and planning, transportation and financial support. Often these care tasks are supplemented, but not substituted, by formal social care services that offer training/support for activities of daily living, entertainment and social interaction, therapy, education and occupation. The various intersections between 'formal' and 'informal' care give rise to various configurations of care arrangements. However, the outworking of social policy in practice ensures that 'informal carers are conceptualised as the mainstay of community care provision while formal carers are positioned as the overseers of the informal care network, providing back-up during times of crisis or when carers are in need of coverage of relief' (Heaton 1999: 765). In rural communities, where the multiplicity of potential care arrangements are delimited by formal service scarcity and geographic dispersion, there is a corresponding contraction of the 'informal care network' and limited, if any, 'back-up' during times of crisis.

The policy discourse of informal care in the community provides a surface of emergence for the subject position of 'carer' (Heaton 1999). This is a dyadic and political subject position that only exists in relation to 'another individual in need of support due to disability, medical condition, including terminal or chronic illness, mental illness, or is frail and aged' (Department of Social Services 2016*a*: 2) and in order to access income support payments, negotiate disability support services and access carer support such as education and respite. Research has revealed that the subject position of carer sits ambivalently with positions of 'mother', 'father' or 'parent', requiring active negotiation resulting in various degrees of uptake, resistance and refusal (*see* Heaton 1999). For rural mothers and fathers caring for a person with intellectual disability in the home and limited involvement with the formal social care service sector, the position of 'carer' may seem antithetical to their identity and values as parents. In normative rural cultures of care-giving, 'good mothers' are resilient selfless carers with an extraordinary capacity for self-reliance

(Bryant and Garnham 2016). Moreover, these cultures are embedded within a broader everyday ethics of rural lifeworlds that valorise self-sufficiency, stoicism and resilience in the face of hardship (Fuller *et al.* 2000; Judd *et al.* 2006; Philo, Parr and Burns 2003). These cultures of motherhood and care-giving normalise and naturalise informal care arrangements and thus cement community care policy in the home and largely privatise struggles to care and provide support to people with intellectual disability. Dyadic care has therefore become the didactic, or morally valorised, model of long-term primary care for people ageing with intellectual disabilities in rural communities. The normative positioning of this model has profound implications for social service support and post-parental care planning.

The 'needs' of the care dyad problematise relinquishing and transitioning care

Whilst carers are also positioned as service consumers in social care discourses and practices, the relational subject position means that carer 'needs' for support are normatively rendered as 'primarily to sustain their care-giving role' (Glendinning, Mitchell and Brooks 2015: 29; *see also* Australian Institute of Health and Welfare 2016; Heaton 1999). In Australia, a new integrated carer support service system is being developed which aims to 'deliver supports that reduce care-giver strain (based on a model of social, psychological, physical and financial outcomes) with the twofold objective of increasing a carer's wellbeing and reducing the risk of the caring role ending' (Department of Social Services 2016*b*: 4). The plan draws on evidence from the USA 'that support services can reduce carer depression, anxiety, and stress and enable them to provide care longer, thereby avoiding or delaying the need for costly institutional care' (Department of Social Services 2016*b*: 4). The economic rationalist ideology underpinning informal care and the provision of carer supports is therefore explicit. Rather than attending to the 'needs' of carers, the plan is therefore a framework that aims to support the sustainability of informal care in the community. This focus is problematised in a discussion paper released by Carers Australia (2016) which points to an over-emphasis on the sustainability of the care relationship and not enough on outcomes for carers in terms of individual support regardless of the sustainability of the care dyad. The relational subject positioning of 'carer' in policy and service therefore problematises the potential 'need' of carers to relinquish care or transition to non-primary care arrangements.

The choice of *not* to provide informal care or to relinquish care requires transgression of normative discourses and entails navigating a path 'against the tide' of the service system installed by the political economy. There is limited empirical research in the field that explores the experiences of carers choosing not to continue in the care-giving role (Larkin and Mitchell 2016). In recognition of the ethically sensitive nature of the topic, Nankervis, Rosewarne and Vassos (2011) decided to forgo data collection with carers who have relinquished care and drew on the experiences of disability service providers with these families. This research illuminated a context of sleep deprivation, violence, property destruction, isolation, family breakdown and desire for a 'normal' life, including being able to support other siblings, as precipitating family relinquishment of care. This research also revealed that families knowingly used the strategy of leaving the person with intellectual disability in respite accommodation as a pathway to access out-of-home permanent accommodation when this option was not directly available to them. However, service providers were often forewarned by families 'that they could no longer cope and that they would relinquish care' (Nankervis, Rosewarne and Vassos 2011: 430) prior to the event. Service providers reported that for families relinquishment was a 'last resort' and that for many a dramatic improvement in quality of life was experienced afterwards and families continued to have a high degree of involvement with the family member with a disability. Whilst sensitive to some families' need for disability-supported accommodation, the research reinstates the dominant discourse of service provision for carers as intended to prevent relinquishment and support continued primary care in the informal dyad.

Social policy for long-term care in the community utilises normative discourses to install disability care in informal dyads, primarily mother–son/daughter relations, that situate primary care and support in the family home. The outworking of social policy through social services allows for limited support to ensure the continuity of the care dyad in ways that problematise relinquishing care or planned care transition to out-of-home disability accommodation. However, this policy and service framework co-exists with discourses of individual choice of services to meet 'needs'. This means that despite structural deficits including chronic shortages of affordable housing, supported disability accommodation and respite services, the onus for care planning and decision-making are centred on the family and, in particular, the primary carer. Equally, the choice of 'not to choose' and of 'not to continue' care are relegated to the margins of 'choice'. It is within the context of these power relations oriented to continuing care that older parental care-givers are experiencing pressure to plan for a transition to post-parental care come illness, incapacity or death.

Service providers are often the voice driving post-parental care planning given their insight into the broader context of disability services and supports. This context is often one of overwhelming demand, and thus lengthy waiting lists, for supported accommodation, disruption to orderly service planning when responding to crisis situations and includes negative outcomes for people with intellectual disabilities resulting from abrupt dislocation without transition support or the opportunity to develop adequate skills in independent living (Bibby 2013; Bigby 2000). These issues may be compounded further by inappropriate or unstable residential placements, significant geographical dislocation from social supports and familiar environments, and the failure of care systems to attend to issues of grief and bereavement in addition to ensuring residential security and primary care arrangements (Bigby 1996; Bigby 2000). The impending 'crisis' of post-parental care is therefore set against a broader 'culture of crisis' that has long plagued the disability sector (Senate Community Affairs Reference Committee 2011). However, the dominant discourse is that services should support families to engage in long-term and post-parental care planning to prevent respite 'bed blocking' and facilitate a smooth transition in accordance with earlier decision-making that will provide the best outcomes for the person with an intellectual disability. The service planning discourse therefore seems misaligned with the delimited material pathways from informal care to supported independent living within the service carescape that delimit agency and freedom of choice in planning. As Bigby (2008: 78) succinctly points out, 'the gross shortfall in availability of accommodation' means that '[r]ather than exercising choice about the location, type of accommodation, and selection of co-residents, adults with ID [intellectual disability] leaving the family home in mid-life may be forced to take the only option available'. The only option, particularly in rural communities, may not be disability-supported accommodation but rather residential aged care, offering a poor match to needs (Bigby 2008).

The responsibility for continuing care arrangements beyond the dyad, and potentially post-mortem, produces a heavy burden of anxiety and uncertainty for older parental care-givers (Bellamy *et al.* 2014; Hussain *et al.* 2014; Iacono *et al.* 2016; Taggart *et al.* 2012). Whilst the discourse on formal planning has been the focus of problematisation, 'Existing programs in Australia for planning for the future are not usually linked to funding, which would otherwise enable families to plan and implement secure housing arrangements for the person with a disability' (Qu, Edwards and Gray 2012: 2). Policy and service reforms occurring in Australia to produce an integrated carer support service include provision for education and training. However, as Carers Australia (2016) note, supports for care succession and lifestage planning relevant to transition to post-parental care are notably absent. This is because education and training are oriented to sustaining the care dyad rather than potentially relinquishing or transitioning care.

Currently in Australia, long-term planning for people with intellectual disability and their older parental carers is situated on the precipice of unfolding policy developments that are transforming the aged and disability care terrain in ways that are yet to materialise. The expectation that older parental care-givers plan for this uncertain and shifting future, in the absence of clear pathways to supported accommodation for aged and disability care, burdens families with sole responsibility for long-term social care. In taking up this focus, post-parental care planning continues to normalise informal care, diverting attention from structural deficits in the socio-political carescape.

Pathways before plans

Problematisation of carers' 'need' to relinquish primary care and for people with intellectual disabilities to make choices about their transition to independent supported accommodation is necessary to unsettle the dominant policy and service discourse around the provision of services to sustain informal care-giving dyads. The increasing longevity of people with intellectual disability means that parental care-givers can now anticipate caring careers that extend for decades beyond their expectation at the birth of their child (Cairns *et al.* 2013). The extended length of these caring careers constitute a non-normative life trajectory (Mckenzie 2016; Pilnick *et al.* 2011; Taggart *et al.* 2012). Ageing parental care-givers are thus arriving at 'older' ages having spent almost a lifetime in care-giving careers. This lifelong commitment may have adversely impacted on their own labour force participation and thus income, social and recreational opportunities, marital stability, and health and mental health outcomes (Carlson and Kittay 2010; Fairthorne, Klerk and Leonard 2016; Irazabal, Pastor and Molina 2016; Qu, Edwards and Gray 2012; Seltzer *et al.* 2011). Whilst research and advocacy highlighting carer satisfaction has challenged representations of care as 'burden', it remains ethically important to acknowledge the social and personal impact of caring careers, particularly, as is often the case with developmental intellectual disability, where caring careers can extend over almost a lifetime, only to cease upon the death of the care-giver. For some families, a lifetime of care-giving can be sustained. For others, this career trajectory comes at tremendous cost and self-sacrifice. Moreover, the normative installation of a lifetime of primary care in the home circumvents the rights of people with an intellectual disability to choice about whether and when to move out of the family home to supported independent living. Opportunities to review the decision to continue or transition care arrangements and potential pathways to a variety of primary care and residential arrangements are needed in the context of life-long planning for people with disabilities across the lifecourse.

Within the broader context of population ageing, the ageing of informal carers and people with intellectual disability is raising questions about the sustainability of long-term social care in the community (Miller and Hayward 2017; Qu, Edwards and Gray 2012). Indeed, within the next decade it is expected that demand for informal care will significantly outstrip supply (Miller and Hayward 2017). The imperative for policy to respond to the forecasted deficits is driving ageing- and disability-sector reforms. Current social policy reform channelled through neoliberal market-driven ideologies for social care in the community, for both disability and ageing, is transforming the service-centric landscape through a care economy in which funding is redirected from 'block'-funded service organisations to individual budgets. The parallel transformations to aged care through Consumer Directed Care and disability care through the NDIS in Australia are premised on increasing quality and satisfaction through consumer control and choice in a care marketplace responsive to demand arising from needs and desires for social services and supports (Foster *et al.* 2012). However, the reforms also seem intended to drive sector innovation to build capacity and the social care economy (Miller and Hayward 2017).

Up until this point in the disability sector, chronic affordable housing shortage combined with cost-efficiencies derived from economies of scale 'has resulted in a crisis-driven, needs-based, vacancy allocation system that seems more service determined than consumer driven' (Wright, Muenchberger and Whitty 2015: 838). A core aim and forecasted ambition of NDIS is therefore to transform accommodation availability and choice for people with intellectual disability. Whilst a substantial investment of the NDIS is being directed to subsidise the supply of new affordable and appropriate housing, the supply will not be sufficient to meet expected demand (Wiesel and Bigby 2015). However, in addition to direct stimulation of supply, it is anticipated that individual consumer budgets will provide a catalyst for social innovation in a variety of community-based models of housing including group homes, integrated housing, and support co-ownership and social housing (Wiesel and Habibis 2015). The policy terrain of the NDIS and disability advocacy emphases the right of people with disabilities to choice about where to live, with whom and with what supports. However, the normative discourse is that with sufficient resources and support, people with disabilities will move out of the family home to independent living. This dominant discourse marginalises the choice of families including a person with intellectual disability to remain living together throughout the lifecourse. Whilst this paper has gone some distance towards problematising this normative arrangement, the right to choose this model of living also needs to be supported. As parental care-givers become older, their capacity to provide care and their own need for care and supports may be impacted by age-related changes to health, mobility and cognitive function. In addition, people with intellectual disability may experience 'premature' ageing or early onset of dementia. To support ageing care dyads 'in place' suggests cross-sectorial innovation is required in housing, services and supports for intergenerational/multigenerational family living.

The philosophy of the NDIS is premised on a marketplace of care services and supports available in the community that is responsive to demand. For people with intellectual disabilities living in rural communities it is likely that demand will be insufficient to mobilise markets and so continued 'block funding' is anticipated to occur where service gaps are identified (Wiesel and Habibis 2015). This arrangement will limit and marginalise opportunities for rural social innovation in disability care. Moreover, it is likely that only large disability service providers will be able to continue to operate residential care options such as group homes in rural communities, thus delimiting choice, and that in the majority of cases informal care in the family home will remain the only 'choice'.

Conclusion

A mid-life transition for people with intellectual disability to out-of-home accommodation and post-parental care upon the death or incapacity of older parental care-givers is systematically instituted in community care policy as the normative condition under which this transition occurs. Whilst this transition is largely to be expected, the point at which it occurs is constituted as a normalised 'crisis' resulting from an absence of a pre-planned pathway but even more significantly, a deficit of affordable and appropriate housing and disability-supported accommodation, that is particularly stark in rural areas. In the absence of care pathways for transition to disability-supported accommodation and post-parental care, the service and policy discourse on formal planning seems misplaced. Shifting the discourse from individual family planning to social care policy and pathways to post-parental care will problematise the 'distribution of care' (Mckenzie 2016) as a socio-political and ethical problem. At present, informal care policy installs and supports care dyads with the agenda of continuing this primary care arrangement. Because of the nature of their long-term dyadic caring formation, the lives of adults with intellectual disability and their parental carers become tightly woven over a lifetime of interdependence and histories of care (Irazabal, Pastor and Molina 2016; Walker and Ward 2013). The need to relinquish or transition care arrangements is thus rendered distressing as older parental care-givers question who will be able to provide care in the same way they have done once they can no longer do so (Bryant and Garnham 2016). Carers' rights should not be conditioned by the requirement to continue as primary care-givers regardless of personal, financial and social impact, and so the right to relinquish care or transition to alternative care arrangements needs to be problematised and addressed in academic and social policy discourse. As Llewellyn *et al.* (2010: 1184, emphasis added) state, carers 'need to be supported to identify, explain and give priority to what they need and want from services *for themselves*'. Through this problematisation, multi-directional pathways can be forged between configurations of informal care and supported accommodation that provide choice for older parental care-givers and people ageing with intellectual disability. It is to this problematisation that a discourse on 'future planning' must respond.

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Address for correspondence:
Bridget Garnham,
Centre for Social Change,
School of Psychology, Social Work and Social Policy,
University of South Australia Magill Campus,
St Bernards Rd,
Magill, Adelaide SA

E-mail: Bridget.Garnham@unisa.edu.au