

Seminar on Carer Navigation of the Health System

Australian Health Policy Institute University of Sydney



**Carers of people with disability and chronic illness: the costs
and benefits of care and policies for carers**

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- ❖ Focus on informal carers of people with disability and chronic illness and ways in which this realm of care through the life-course is experienced in Australia and addressed in policies and services.
- ❖ social-economic and political circumstances of care-giving: trends in Australia and other comparable countries towards increased reliance on, and to varying extents policy recognition and support of, informal care within households and inter-generationally across households, especially within contexts of population ageing.
- ❖ The caring population is diverse and heterogeneous: the paper will provide trends for carers of different ages and for Indigenous people
- ❖ Caring is gendered - men and women participate, but to different extents and in different ways
- ❖ Caring has significant impacts on the wellbeing, health, standard of living and access to employment and income of care providers.
- ❖ Two case studies will be presented: children and young carers (aged up to 24 years) and adult carers of employment age, paying attention to the costs relating to reduced participation in education and employment.
- ❖ The presentation will also identify the policies and services that have been shown to support and assist carers, both in their care-giving responsibilities and in facilitating their inclusion in education and employment.

Case Studies explored



- ❖ Conceptualisation of social care with respect to two case-studies of care-provision in Australia
- ❖ Children and young people providing care for a family member - young carers
- ❖ Carers of workforce age caring for a disabled or chronically ill spouse, or disabled offspring, or other relative, often an aged parent
- ❖ How do concepts of “social care” help to explain these relationships and how are informal and formal care provision interconnected in these case-studies?
- ❖ Socio-economic context: increased longevity, falling birth rates, changes in family structure, increased educational attainment of women and increased labour force participation of partnered women and mothers, increased proportions of very old people requiring care, official fear of increased dependency ratios.

Dissolving the dichotomy of formal/informal care: the concept of “social care”



Four dimensional conceptualisation of social care (Adaptation of Daly and Lewis (2000))

- ❖ *Care is labour*: requiring consideration of whether care is paid or unpaid, formal or informal and the different social policies determining these porous and interconnected modalities. Informal care of older people and people with disability or severe illness involves time that involves work. Bittman et al (2005) using the ABS Time Use Survey found that most caregivers undertake the equivalent of a part-time job to assist and support a family member or friend. In 2003, almost half of primary carers (48%) had hours of caring at least equivalent to a traditional full-time paid job of 40 hours or more per week (ABS, 2008).
- ❖ *Care is located within a normative framework of obligations and responsibility*. It is misleading to consider care only within the framework of labour. Care is a relationship. many informal carers do not identify themselves as carers and do not use available services, because their care-giving is embedded in a deep sense of obligation.

- ❖ *Care is an activity with financial and emotional costs:* direct costs of care and opportunity costs: reduction of labour force participation, leaving the labour force entirely, reducing hours of employment, reduction of personal and household income, increased experience of indicators of deprivation compared with people who do not provide care; emotional and health-related costs (Bittman, Hill and Thomson, 2007; Hill and Thomson et al, 2008). These are not just point-in-time costs, but may result in difficulties with labour force re-entry when caring responsibilities cease, and on retirement incomes. These life-course costs are borne predominantly, but not entirely, by women as primary carers.
- ❖ *Informal care-giving and employment are juggled (perhaps balanced?) in different ways and to different extents,* depending on the type of care provided, and sometimes on combinations of care provided by the same caregiver, predominantly women with child care and elder care responsibilities; the stage of the life-course, the labour market and employment circumstances and caregiver's educational qualifications and earning capacity, and the system of formal services for care recipients and providers.

Increased labour force participation and the perceived “problem of Care”



- ❖ Government policy in Australia, and similar OECD countries, is focused on further increasing the overall level of labour force participation, particularly that of women, older people and people with disability.
- ❖ Policy attention is focused primarily on promoting, encouraging or mandating participation in the market economy, and the challenges posed to governments, communities and above all families of providing care for children and adults rendered vulnerable by disability, severe illness or old age are perceived and treated largely as a private problem, requiring private solutions through familial, informal care in which care and employment are juggled, or in some ways “balanced”.
- ❖ This difficult, sometimes impossible balancing act may create direct and opportunity costs to informal carers with respect to their employment participation and income, strain on physical and mental health and personal relationships. Costs accumulate over the years of care-giving, and may impact negatively on well-being and on income in retirement. At the same time, many carers speak of their sense of commitment and love for the people for whom they care, and their appreciation of the benefits of the care which they provide.

- ❖ Care cannot be further re-familialised because of the strong increase in women's educational retention and attainment since the 1960s, their increased labour force participation, later age of child birth and smaller family size, although the demands of elder relative care and spouse care have not diminished, and are likely to increase in the context of an ageing population.
- ❖ Care cannot be fully commodified, because it is concerned with caring about as well as caring for, because it is emotional and relational, because it incurs not only very substantial costs and but also provides very substantial worth.
- ❖ The increasingly pervasive adult worker model (expected to apply equally to women and men) fails to recognize adequately, effectively and equitably the issue of care and how care needs should be met. A case must be made for the recognition of care work as worthwhile and necessary, which involves valuing it.
- ❖ Care is *the* essentially human activity.

Rates of Caring (from Census 2006, ABS 2008)

❖ For Non-Indigenous people

- Male carers proportion of all NI males: 8.8%
- Female carers proportion of all NI females: 13.4%

❖ For Indigenous people

- Male carers proportion of all Indigenous males: 10.4%
- Female carers proportion of all Indigenous females: 15.7%

Note cultural differences: In 2006 Indigenous Australians aged 15-34 were about 1.8 times more likely to be carers than non-Indigenous people

Indigenous Australians aged 35-44 years were 1.4 times more likely to be carers than non-Indigenous people

Related to earlier onset of long-term health conditions and disability in Indigenous population. The carer rate after 65 years was similar for Indigenous and non-Indigenous people. (ABS, 2008)

Note Gender differences: In both Indigenous and non-Indigenous population, women have significantly higher rates of care-giving than men.

- ❖ Point-in-time and over-time analyses of the Household, Income and Labour Dynamics in Australia (HILDA) data for people caring for a disabled or sick family member have found a significant “caring penalty” with respect to labour force participation and income (Thomson et al, 2005).
- ❖ Intersections of child care and other modes of care: More than 50% of Australian mothers whose youngest child is under 15 are employed part-time. The prevalence of part-time employment for partnered women and mothers is one of the key factors likely to be conducive to the familialisation of other forms of care, in particular elder care. 70% of all informal elder care is provided by women.
- ❖ Over 90% of people aged under 65 years in need of assistance receive support from family or friends, compared to only 26% who receive assistance from formal care providers - some receive both forms of care (AIHW, 2005: 249).
- ❖ Carers themselves report higher than average levels of disability increasing with age:
 - Aged 15-34: rate of reported disability is 20%
 - Aged 35-64: rate of reported disability is 35%
 - Aged 65+: rate of reported disability is 61%

Gendered experiences of care: the labour market and policy contexts



- ❖ The Australian labour market over the last 25 years provided increasing amounts of part-time employment, and hours worked have remained fairly steady at sixteen per week, but at the other end of the labour market, there has been work intensification, taking Australian full-time employees to the long end of the working-hours spectrum.
- ❖ spill-over effects to care, minimising the role of men in care: Australia is a one-and-a half adult earner model and predominantly a female carer model, with some changes in a positive direction, particularly with respect to time spent by men in child care and spouse care when the spouse has a disability or is frail aged. However, the one-and-a half earner model brings gendered penalties.
- ❖ Use of services: Access to effective formal services is of critical importance and supports the continuation of labour market attachment (Hill and Thomson et al, 2008). But service use is low. Availability, cost, appropriateness and flexibility of provision effect carers' access to and use of available support.

- ❖ ‘Young carers’ is the term used in Australia, UK and the USA to refer to children and young adults with informal caring responsibilities for other people, usually family members, who have a chronic illness, physical or mental disability. Young carers: children and teenagers to age 17, and young adult carers aged 18-24.
- ❖ ‘Young carers’ with respect to their activities and responsibilities have a long history, but being identified and named as a social category is recent. Young carers have become the subject of research and government policy deliberation in Australia following non-government sector advocacy giving carers and young carers a political voice, through the state and national Carers Associations. Research into the characteristics, circumstances, needs of young carers and their care receivers and the policy frameworks of these care-giving relationship is also recent (over the last decade).
- ❖ Our research places young people’s care-giving in a framework which sees them as active agents within their families and communities.
- ❖ Agency operates within constraints: familial and kinship obligations; socio-economic and demographic constraints including low-income and lack of resources; and policy and service constraints.

Numbers and demographic characteristics of young carers



- ❖ In 2003 (ABS 2005), there were 347,700 carers up to the age of 24 years, of whom 18,700 were 'primary carers'. Primary carers are defined as carers who provide the most informal assistance, in terms of help or supervision, to a person with one or more disabilities, where the help is ongoing, or likely to be ongoing, for at least six months and 'be provided for one or more of the core activities communication, mobility and self care'.
- ❖ The gender composition: females comprise 48.7 per cent of all young carers, and 75.4 per cent of young primary carers, and with regard to carers aged 18-24, young women are 80 per cent of primary carers - ie by far the majority of young people with the main responsibility for care-giving (those who provide most of the informal help, assistance, support or supervision) are girls and young women. Possibly induction into life-course caring responsibilities, accounting for the earlier age at which women commence caring responsibilities.
- ❖ Two thirds of all young carers care for a parent; 43 per cent caring for their mother, and 23 per cent for their father

Socio-economic Circumstances



- ❖ Constraints on participation in school education, post-secondary education and training,
- ❖ Constraints on access to employment, with implications for short and longer term employment histories and income circumstances
- ❖ Constraints on participation in friendship networks, social, cultural and recreational activities, with resultant impacts on social integration and personal health and well-being
- ❖ young carers more likely than their peers to have a disability or long-term health condition themselves
- ❖ Young carers more likely than other young people to be in a sole parent family;
- ❖ To live in socio-economically disadvantaged areas
- ❖ and be of a non-English speaking background
- ❖ Caring giving is more prevalent amongst Indigenous young people, in particular young women (Census 2006)

Employment and income correlates of care- giving



- ❖ Constraints on employment participation for carers aged 15-24: For male young carers compared with non-carers: lower percentage in F/T employment, significantly higher percentage in P/T employment, and slightly higher percentage unemployed
- ❖ For female young carers compared with non-carers: lower percentage in F/T employment, slightly higher percentage in P/T employment, and significantly higher percentage unemployed
- ❖ Multivariate analysis of young-carers' employment (sample size 4693) - Controlling for age, education qualifications, CALD status and whether the young person has a disability

Key result: Primary carers less likely to be employed than non-carers (marginal effect: -19 percentage points)
- ❖ Carers somewhat less likely than non-carers to have wages as main income source; more likely to rely on income support
- ❖ Household income: approx. 40% of young carers are in households in the two lowest income quintiles compared with about 25% of young non-carers: financial vulnerability of care-giving, combined with family illness or disability (All findings from Cass, Smyth, Hill and Blaxland, 2008 (unpublished report forthcoming))

Use/non-use of formal services



- ❖ In Australia, the majority of carers under the age of 25 whose care recipients needed assistance did not use formal services (Bittman et al, 2004; Thomson et al, 2005).
- ❖ Reasons: many young people do not identify as a 'carer' and consider that they do not need to access formal services - normative relationships of familial care giving within an accepted understanding of obligation and responsibility sit at the heart of their sense of identity.
- ❖ Others reasons for not using formal services: characteristics of the services; the targeting of services bypasses their particular needs; services are not available, or have inconvenient hours of operation, or are not affordable.
- ❖ service providers lack awareness about the needs of young carers; young people and their family do not have access to information about services; transport difficulties; and, of major importance, because of young peoples' mistrust of services and reluctance to use them.
- ❖ Obligations of family life: 76 per cent of young primary carers stated that they took up their roles because they could provide better care than someone else, or that it was the responsibility of a family member to provide care, or because of emotional obligation. (SDAC 2003)

- ❖ *Care is labour*: occupies time which would otherwise be available for participation in education, training, employment and social/friendship activities
- ❖ *Care is located in a normative framework*: young people may not identify themselves as carers but as family members carrying out their responsibilities and obligations. Young informal carers are attempting to harness scarce resources, substituting a normative economy of care for recourse to paid, formal care, which they and/or their family consider either inappropriate, not affordable or inaccessible.
- ❖ *Caring incurs costs to education, employment, income and mental health*: young carers more likely than peers to be in low income households, affecting access to services and supports. Over-representation of young people of CALD and Indigenous backgrounds among identified carers indicates that the costs of care may be disproportionately borne. And given the greater likelihood of being a primary carer among young women, these are gendered costs.
- ❖ How might the nature and intensity of care be altered under different policy frameworks, so that a young person's normative ethic of "caring about" and "caring for" need not necessarily be extended into "taking care of"?

Caring During Workforce Years



- ❖ Women comprise 56% of all carers of workforce age, but 76 % of primary carers
- ❖ significant tensions in managing paid work and care-giving for carers of workforce age (15-64): high rates of non-labour force participation; high rates of part-time employment; significantly lower median gross weekly income; greater likelihood of relying on government income support as the principal source of income – with particular disadvantage for primary carers (ABS, SDAC 2003).
- ❖ Carers of workforce age unemployed or not in the labour force:
 - 46% of women;
 - 26% of men
- ❖ Full-time or Part-time employment for employed carers
 - women carers employed full-time: 44%
 - men carers employed full-time: 80%

These figures indicate gendered differentiation in care-giving responsibilities, usually based on the intensity of care provided by women as primary carers.

Also indicate the challenges faced in juggling informal care and employment.

Women carers state that employment represents not only income but social participation-”respite”

Barriers to Employment at workplace level



What characteristics of employment increase the probability of employees leaving the labour force once they become carers?

Article by Hill, Thomson, Bittman and Griffiths “What kinds of jobs help carers combine care and employment?” forthcoming in the AIFS journal *Family Matters*, indicates that at the onset of caring, the following employment characteristics are least conducive to continuing employment:

- ❖ being a casual rather than a permanent employee;
- ❖ working part-time;
- ❖ having no supervisory responsibility;
- ❖ working for a smaller firm (less than 100 employees);
- ❖ lack of autonomy in the workplace;
- ❖ not belonging to a union;
- ❖ lack of access to any carer-friendly workplace arrangements;
- ❖ and above all, carers’ perceptions that they have poor job security.

On the other hand, access to at least one carer-friendly work place arrangement like special leave for caring; permanent part-time employment; flexible start and finish times or home-based work improved carers chances of staying in employment. Having secure, part-time employment was most significant.

Effects of care on health and well-being



❖ Effects of caring on well-being: Primary carers (ABS (2003) SDAC)

Clear evidence of satisfaction as well as stress

- Primary carers who felt satisfied as a result of caring role: 26%
 - Primary carers who stated that they felt weary or lacking energy: 34%
 - Change to overall physical and emotional well-being due to caring: 29%
 - Diagnosed with a stress-related illness: 10%
- ❖ The impact of care-giving on health could be attributed to the difficulties of juggling employment and care, or to the loss of employment and income attendant upon taking up care-giving responsibilities.

Conclusions

- ❖ *Care as labour* care of children and adults who are frail elderly, or have a disability or chronic illness involves time which is work in every sense.
- ❖ *Care located within a normative framework of obligations and responsibility.* Policy development cannot look only to formal services to provide all care, since care-giving and receiving involves a relationship from which both may parties derive benefits, as well as costs.
- ❖ *Care as an activity with financial and emotional costs.* The costs involved are reduction of time spent in education and training, and/or labour force participation, reduction of income, emotional and health-related costs. These are not just point-in-time costs, but may have life-course impacts on employment and income history, and on retirement incomes.
- ❖ All of these experiences are deeply gendered: both men and women are carers, but to different extents and in different ways.

By way of conclusion: for policy debates



- ❖ A minimum of 12 months' paid leave for caring purposes which recognises periods of the life-course when care is required for a spouse, child, relative or friend made vulnerable by disability, illness or old age. This would be accompanied by the guarantee of return to a similar job. This would be treated like a "time-bank" of care credit entitlement over the duration of paid working life.
- ❖ Strengthening of the conditions of part-time employment to resist further casualisation and erosion of benefits and conditions and reduction of long-hours employment intensification: permanent rather than casual part-time employment.
- ❖ The statutory right to request flexible and reduced working hours for employees with elder care and disability care responsibilities (cf UK provisions).
- ❖ Extended provision of affordable, publicly subsidised, accessible and good quality aged and disability care services, which are flexible and tailored to users and carers' diverse needs, in particular through innovative packages of support which sustain living in community.

- ❖ Elder and disability care to be provided by skilled providers and the value of their skills and contributions recognised through equitable wages, good working conditions and in-service training to improve skills.
- ❖ Enhanced support for care through the income support system, to give adequate support to the carers of children and adults with disabilities, and the problems of frail age, involving a re-design so that packages of care and employment may be supported with partial income support, as well as formal care services. Financial recognition of the direct as well as indirect costs of care.
- ❖ Also crucial is supported return to employment when care-giving ceases or diminishes, through education, training, retraining and employment support.

This modest agenda is put forward to provide a base for extended conversations among researchers, policymakers, service providers and employers at government, community sector, union, employer and workplace levels - conversations which listen to the voices of informal carers, older people, people with disability and service providers.