



ways to work

Employment support for carers of adolescents
and adults with an intellectual disability

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of adolescents and adults with an
intellectual disability.

Penny Paul

Coordinator, Carer Consultations,
Carers Victoria, March 2010.

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Acknowledgments

Carers Victoria consults with caring families in order to shape policies and services that reflect the needs and preferences of caring families. In this report, the focus is on outside-centre-hours and vacation care for adolescents and adults with an intellectual disability and their families.

We would like to thank the participants, each of whom gave a substantial amount of their time to complete the study which was used as a basis for this report. Particular thanks go to those participants who expressed study fatigue but participated anyway, with the expectation that they might at last see tangible outcomes.

To discuss the report, please contact Penny Paul, Coordinator, Carer Consultations or Gill Pierce, Program Manager, Policy and Research at Carers Victoria.

Front Cover

I have a son Daniel, he is blind, has paralysis down his left side, temporal lobe epilepsy and a profound intellectual disability. He cannot communicate other than to sign 'more', he is incontinent and requires help with every task. When Daniel was nine and I was studying for a degree I found out that the local school holiday program for teenagers had lost its funding. I started to advocate for families who required these programs but had only limited success with pilot projects. When Daniel was 14 I was told by the local council that they could no longer care for Daniel in their school holiday program which was a relief in one sense because he was very unhappy going to the program.

When I was asked to comment on this report I had just received a third email informing me that my son's funding package was being rejected because DHS will not pay for Daniel's care while I go to work. Daniel is 18 this year and although I have held my job for six years the only guarantee I have that I will be able to continue to work is the funding I beg for every year. I am emotionally exhausted from this ongoing battle. I have many years ahead of me and I have a great deal that I want to contribute to my family and the community. This report highlights some of the complexities faced by people like me who just want some hope and normality in their lives. I am pleased to see some ideas and answers to these issues.

Sally

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Glossary

Terms

Adult offspring	A study participant's adult son or daughter who has an intellectual disability.
Aged Pension	An income support payment for people of retirement age.
Interdependence	The shared interests and interconnected life events which impact on adults with intellectual disability, their primary carer and other members of caring families.
Family centred practice	An approach to the provision of service that begins with the needs and aspirations of all members of caring families.
Carer Allowance	Income supplement paid to eligible people who provide a minimum of 20 hours of care per week.
Carer Payment	Income support paid to carers who provide more than 40 hours of care per week and who meet the requirements of the income and assets test.
Caring	Providing a range of assistance for a person with a disability or chronic illness, including emotional support, advocacy, planning, supervision and personal care.
Caring dyad	A primary carer living with their adult offspring in a two-person household.
Caring family	All members of a family who have a role in providing support and care for one or more of its members with an illness or disability.
Community care	Support services provided to people with an intellectual disability to enable them to remain living in their own or their family's home.
Disability Support Pension	The Disability Support Pension is a payment for people whose physical, intellectual or psychiatric impairment prevents them from working, or for people who are permanently blind.
Newstart Allowance	Provides financial support to people of working age while they are looking for work.
Primary carer	The person in a caring family who does most of the caring.
The service system	Funded disability and Home and Community Care (HACC) services which are provided to adults with an intellectual disability and their carers.
The 25 hour rule	Carers in receipt of the Carer Payment may not work or study more than 25 hours per week including travel time.

Acronyms

ABS	Australian Bureau of Statistics
ACD	Association for Children with a Disability
DHS	Department of Human Services (Victoria)
DSP	Disability Support Pension
DEEWR	Department of Education, Employment and Workplace Relations
EMTR	Effective marginal tax rate
HACC	Home and Community Care
HILDA	The Household, Income and Labour Dynamics in Australia Survey is a household-based panel study which began in 2001. It collects information about economic and subjective wellbeing, labour market dynamics and family dynamics.
HREOC	The Human Rights and Equal Opportunity Commission
NATSEM	The National Centre for Social and Economic Modelling
NGO	Non-government organisation
OECD	Organisation for Economic Co-operation and Development
TOCC	Taskforce on Care Costs

1 Executive summary

The reduction in labour supply forecast in the Intergenerational Report (Treasury 2010), creates a pressing need for governments to develop policies that boost labour force participation to underpin Australia's future economic growth.

The report details how recent significant increases in labour force participation have largely been the result of increased female participation rates. It attributes this to a range of factors including: greater female educational attainment, changing social attitudes, and better access to child care services and part-time work. Female labour force participation is supported by a range of government initiatives including personal income tax cuts, increases in the Child Carer Tax Rebate and Paid Parental Leave. However, the increase in labour force participation has been uneven. Segments of the population continue to face multiple and persistent disadvantage. Disadvantage affects the lives of individuals, families and communities, and impacts negatively on labour force participation, productivity and governments' fiscal sustainability (Treasury 2010). There are a number of interventions that governments can make to reduce disadvantage. *Ways to Work* makes six evidence-based recommendations to address the particular disadvantage of long term family carers.

The impact of caring on economic and social participation is a key concern of Carers Victoria and the Australian Network of Carer Associations. This report highlights the need for appropriate services to enable carers to combine unpaid care with labour force participation.

Previous studies have highlighted the financial and economic impact of providing unpaid informal care to family members (Nepal 2009; TOCC 2007; AIHW 2007; Lymer, Percival & Harding 2006; Access Economics 2005). In particular, these studies have highlighted the difficulties many primary carers face participating in the labour force. There is a body of research that has identified that primary carers with long-term caring responsibilities are at particular risk of social and economic exclusion (Edwards et al. 2008; Nepal 2009; TOCC 2007). Other studies have focused on the impact of caring responsibilities on carer health and well being (Edwards et al. 2008; Cummins et al. 2007; Gill et al. 2007; Edwards, Higgins & Zmijewski 2007).

This report aims to complement these prior studies by examining the delivery of services to adults with intellectual disability and their caring families. It documents the reflections of some primary carers on how services could be improved to assist them combine labour force participation with unpaid caring.

Ways to Work examines the experiences and circumstances of 21 female primary carers of people (over 18 years of age) with an intellectual disability. As a small scoping study, it aims to investigate and document the labour force participation of family carers, whose lives are shaped by the support needs of an adult offspring with an intellectual disability. Carers were surveyed about their:

- labour force participation
- experience of the current service system to support their labour force participation; and
- preferences regarding models of service delivery that would better support them combine their caring role with labour force participation.

Ways to Work investigates the participants' experiences of the service system as an enabler or a barrier to labour force participation. The service system in this context includes adult disability services funded by Department of Human Services (DHS) and delivered by non-government organisations (NGOs), respite services, and Home and Community Care (HACC) services that are delivered by a combination of NGOs and local governments. It includes a range of other voluntary, community, and private supports.

Currently, there is a problematic dichotomy underpinning service provision. Services are delivered either to an adult with an intellectual disability or to their carer; however, the lived reality of caring families is one of interdependence. The term interdependence is used in this report to describe the shared interests of and interconnected life events which impact on adults with intellectual disability and other members of their caring families, most notably their primary carer. 'Interests' consist of a range of social, emotional and economic needs and preferences. The experience of interdependence is amplified in caring dyads, where a primary carer lives with their adult offspring in a two-person household.

This study demonstrates the way in which services provided for adults with an intellectual disability directly influence carers' lives, specifically their capacity to both care for a person with a disability and participate in the labour force. The eligibility requirements, costs, modes of access, practices and policies of services directly affect the carers' social and economic participation. This is one of the reasons why a number of carers participating in this study share the social and economic isolation that characterises the lives of many people with an intellectual disability.

Within the current arrangements adult disability day services provide services for 45 weeks a year between the hours of 9 am and 3 pm. Adults with an intellectual disability may also access support with their personal care and various respite and recreation programs to facilitate participation in the community. Outside of these formal services, they depend on their family and community for care, support and social relationships.

This study found that the current organisation of both disability and respite services tends to exacerbate the precarious attachment many primary carers have to the labour force. The impact of child-rearing on women's labour force participation has been a strong focus of researchers and academics. It has prompted the Commonwealth Government to develop a large range of financial and social arrangements to support women's labour force participation.

The Commonwealth Government provides support to women with young children through the provision of income support, allowances and tax rebates, including Paid Parental Leave (from 1 January 2011), the Baby Bonus, Parenting Payment, and Family Tax Benefit. In addition, the Child Care Benefit and Child Care Rebate support the labour force participation of families with young children. There is also legislation to protect women against discrimination on the basis of pregnancy or family responsibilities, and the right to request flexible work arrangements to accommodate child-rearing responsibilities.

A family's need for substitute care generally wanes when children reach adolescence. By contrast, parents of children with intellectual disability continue to need access to flexible work arrangements, income support, and access to substitute care throughout the life course of their offspring, in order to combine paid work with unpaid caring. The current service system for people with intellectual disability tends to assume a model where a stay-at-home mother/carer is able to provide transport, care and supervision to

her offspring indefinitely. Of the 21 carers surveyed, only one had access to a program that explicitly supports her labour force participation (See case study: Karingal's Care to Work program).

For carers, access to appropriate outside-centre-hours and vacation care throughout the life course of the person with an intellectual disability is a fundamental requirement. Substitute care services can ensure parent carers and caring families can make real choices around their labour force participation. The responses of long term family carers who participated in the study provide the beginnings of an empirical evidence base for policy and program development in this area.

2 Summary of recommendations

To address the disincentives for carers to work, Carers Victoria recommends:

Recommendation 1

That Commonwealth Government remove the current disincentives for carers in receipt of income support payments to combine informal care and paid work. This can be addressed in the context of its response to Australia's Future Tax System Review.

- Particular attention should be given to examining the impact that effective marginal tax rates, the 25-hour rule, and eligibility for the Health Carer Card have on the labour force participation of carers.

Recommendation 2

That the Commonwealth Government, through the Department of Education, Employment, and Workplace Relations (DEEWR) guarantees that Carer Payment recipients have access to training to maintain, develop and increase their workskills. This will assist them to enter or re-enter the labour force when they are able to do so.

- It is essential that the Productivity Places Program allocates priority places to carers.
- It is essential that Centrelink determines eligibility and refers new Carer Payment recipients and renewed recipients to the Productivity Places Program.

Carers in the workplace

Recommendation 3

That Commonwealth and State Governments, their agencies and peak employer bodies actively promote carer friendly workplace practices.

Recommendation 4

That the Commonwealth Government amend Section 65(1) of the *Fair Work Act 2009* to extend the right to request flexible working arrangements to all family carers across the life course. This will include those caring for adults with a disability or chronic illness and those caring for adults who are frail and ageing. It would ensure equitable support for all caring families.

Services to support carers to participate in employment

Recommendation 5

That the Commonwealth and State Governments amend policy and funding guidelines for respite programs and the Home and Community Care (HACC) Program, to recognise and support greater employment participation for carers. The availability of regular, predictable and ongoing respite hours is vital for caring families and will underpin the work force participation of carers.

Recommendation 6

That the Commonwealth and State Governments work collaboratively to ensure the availability of recurrent funding to develop outside-centre-hours programs for adolescents and adults with an intellectual disability including:

- **Activity and community participation programs which can be developed from existing day program venues from 8 am – 9 am and 3 pm – 6 pm daily, and during centre vacation periods; and**
- **Collaboration and partnerships between parents and service providers in the planning and development of programs with shared transport arrangements.**

3 Background

Carers Victoria became aware of the importance of outside-school, outside-centre-hours and vacation care for people with an intellectual disability whilst working with a parent advocacy group. A number of parents had been forced to leave the workforce in order to provide care for adolescents with an intellectual disability. There were inadequate supports available in the form of outside-school-hours care. In 2005, these parents established *Casey Kidz Klub* to provide outside-school-hours care for adolescents with intellectual disability; a service which has now attracted government and community funding.

The parent activists involved with *Casey Kidz Klub* were aware that as their children transitioned to adulthood they would again be faced with the problem of a lack of outside-centre-hours and vacation care. This would place pressure on their ability to participate in the work force, reduce vital family income, and for many families, create extreme anxiety about their capacity to maintain mortgage payments and ensure secure long term a housing.

The Association for Children with a Disability (ACD) report, *Moving Beyond the Catch 22* (Mathews 2009), details the need for outside-school-hours and vacation care for adolescents with an intellectual disability. *Ways to Work* progresses this on the basis of research, this report demonstrates the need for quality, affordable and appropriate substitute outside-centre-hours and vacation care for both adolescents and adults with intellectual disability.

4 Literature review

Families who provide unpaid care at home for one or more of their members are a vital part of community care for people who are frail aged, have a disability, mental illness or chronic health condition. According to the ABS there are 2.6 million carers in Australia (ABS 2003). They provide a valuable and necessary service caring for family members in the home. The most common reasons carers cite for providing care is family responsibility, the feeling that they can do a better job than others, and emotional obligation (ABS 2008: 8).

As the work of family caring is informal, linked to private space, family responsibility, obligation, and emotional attachment, it is a particular form of labour that is distinct from the paid workforce. According to the Australian Human Rights Commission (formerly known as Human Rights and Equal Opportunity Commission HREOC):

...the seemingly 'private' decisions about arranging paid work and caring work are in fact shaped by the public context in which they are made: for example, the employment options available to families in particular communities, the availability of child and aged care, or the taxation implications of re-entering the paid workforce (Squire and Tilly 2007: xiii).

The socially structured separation of private and public labour affects the capacity of carers to combine their caring role with paid work. In particular, it has an adverse impact on their capacity to maintain independence and autonomy and restricts their choice to participate in the labour force if they wish to do so. The benefits of labour force participation are well-established. Meaningful employment provides financial independence for the individual and their dependents; it also has a range of social and health benefits that are linked to improved quality of life for the individual. These benefits come from increased contact with the broader community and stronger networks which enable the individual to maintain a balanced life and increase their resilience and coping abilities when faced with stressful or crisis situations (Taskforce on Care Costs: 2007, Gray, Edwards & Zmijewski: 2008 and Lymer, Percival & Harding: 2006).

Family carers face many challenges in their engagement with the paid workforce. They are likely to experience long periods of disengagement from employment and broken work patterns due to the demands of caring. They are often in low paid, part-time and casual work. In 2003, primary carers were more likely to work part-time than full-time (ABS 2008: 5). *'They tend to have lower incomes, labour force participation and completion of year 12 or equivalent than non-carers'* (ABS 2008: 8). Many carers also face financial difficulties. In 2006, over one-fifth of all carers (22%) had taken actions such as borrowing money in the previous 12 months; 19% had experienced cash-flow problems; and 15% had difficulty paying bills (ABS 2008: 5).

A significant impact upon the capacity of carers to engage in paid work is the time spent caring and the low economic and social value placed on labour performed within the home. In 2003, almost half of all 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: 5). According to Brian Howe (2007) income support in Australia needs to be revised to reflect the reality that providing unpaid care is a legitimate reason for being out of paid employment. He argues that the number of people needing care in Australia is steadily

rising. People with a disability or illness, their families and governments have a strong preference for care in the community. Income support mechanisms should normalise caring and provide individuals with support over the life course and across transitions from employment to caring, caring to study, and caring back to employment.

Howe (2007) argues that individuals who provide long-term intensive care are currently denied opportunities to maintain or develop work skills while they are caring. This disadvantages them further when looking for work becomes possible. Many primary carers must take on casual work either because of a loss of work skills or to ensure they have flexibility in hours worked. Casual workers have reduced opportunities to undergo workplace-supported training and this compounds the problem. Casual and tenuous work arrangements also fail to provide the opportunity for individuals to accumulate adequate superannuation savings, increasing their dependency on the Age Pension in retirement.

Female primary carers with long-term caring responsibilities constitute a particularly *at risk* segment of an already disadvantaged group in our society (Nepal 2009, Howe 2007). Women are comparatively more likely to be financially disadvantaged than men. A higher proportion of carers are women, and women are more likely to take on caring responsibilities at an earlier age (ABS 2008). A study by Gray et al. (2008) showed that the caring role was usually undertaken by family members who have lowest earning capacity. However, the study found that 53.6% of the unemployed women who receive the Carer Payment wanted to work (Gray et al. 2008:32).

The barriers to workforce participation faced by primary female carers are elaborated in a study by Edwards et al. (2008). The most common barriers reported by female carers in receipt of the Carer Payment who would like to be in the labour force include:

- the lack of alternative disability care arrangements;
- fear of disruption to the person with the disability;
- the difficulty of arranging working hours;
- a loss of skills from being out of the workforce; and
- the cost of paying for disability care while at work (Edwards et al. 2008:106).

To sustain the Australian economy, governments need to minimise the number of people dislocated from the labour force and to maximise workforce participation of people of working age (Howe 2007). Structural changes to the Australian economy over the last three decades have fundamentally changed the labour market. There has been a rise in two-income households at one end of the spectrum, and a tightening of spending on income support and social services at the other. In addition, the ratio of Australians of workforce age will decline from its current level of five people to support every person aged 65 and over, to a projected level of 2.4 by 2047 (Australian Government 2007). This creates a strong imperative for all Australians of workforce age to participate in paid work.

Given the anticipated reduction in labour supply, there is a pressing need to develop policies to assist carers in balancing paid work and unpaid caring. This will boost labour supply and decrease carer dependency upon income support payments such as Carer Payment, Carer Allowance, Disability Support Pension and the Age Pension. In addition, Howe (2007) highlights the need to introduce new measures to reduce the barriers

faced by Carer Payment recipients to increase their hours of work. These include modification to the 25-hour work, training and education threshold and adjustment of the currently excessive Effective Marginal Tax Rates (EMTRs). These reforms would reduce the segmentation of the population into two-wage and no-wage households and address intergenerational disadvantage faced by no-wage families.

The preference of carers to engage in paid work, for both their economic and social wellbeing, has been established by previous studies and is confirmed by the Taskforce on Care Costs (2007), Gray, Edwards & Zmijewski (2008) and Lymer, Percival & Harding (2006). The Taskforce on Care Costs recommends that financial support for carers should be considered as a strategy to support their workforce participation and reduce their dependence on income support.

A study by Binod Nepal (2009) for the National Centre for Social and Economic Modelling (NATSEM) and Carers Australia examines the impact of the primary carer role on the health and economic well-being of women over their working life. He compares the economic and health outcomes of female primary carers with women who share their general characteristics but who have no caring responsibilities. His study found that:

- Depending on their level of education, mothers caring for a child with a disability are likely to earn between a 1/4 and a 1/2 of the income of women with the same characteristics who are not primary carers, over their working life.
- While mothers caring for children with a disability receive higher levels of government benefits than other women, these payments do not fully compensate for forgone earnings from paid work.
- The level of superannuation accumulated by women who have been out of the workforce caring for a child or children with disability for a significant part of their life will be insufficient to provide for an adequate retirement (Nepal:2009:ix).

The Taskforce on Care Costs (2007) investigated the financial cost of care and the personal, social and economic impacts of care on labour force participation. Individuals and families who are engaged in long-term caring report that the impacts of their reduced workforce participation or separation from the labour market are two-fold: they are socially excluded and economically marginalised. The study found that:

The strategies which would most assist carers to balance their work and caring responsibilities are (i) improved access to support services; (ii) greater workplace flexibility; and (iii) improved quality of support services (TOCC 2007:5).

In addition, the report suggested that improving the quality of and access to support services such as respite care is essential for carers' workforce participation. This is supported by the 2003 ABS Survey of Ageing, Disability and Carers. It found that 17% of primary carers reported the need for access (or further access) to respite care (ABS 2008:5).

The Association for Children with a Disability report, *Moving beyond the catch-22: Outside school hours care for young people with a disability* (Mathews 2009), demonstrates the need to extend the availability of outside-school-hours care for adolescents with an intellectual disability to support their parents' workforce engagement. Outside-school-hours care is generally targeted to children between the ages of five and 12 years. This report argues that children with disabilities aged 12 to 18 and their parents need access

to programs before and after school, and during the 10 to 12 weeks of school holidays per year, if they are to retain their workforce engagement. They require services that:

- provide meaningful activities in a safe and appropriate environment;
- provide opportunities for community inclusion;
- are staffed by knowledgeable, supportive and qualified care workers; and
- are sustainable through the provision of recurrent funding (Mathews 2009:12).

Providers of integrated outside-school-hours care programs reported to Mathews that these programs cost significantly more to provide than non-integrated programs. The extra funding required comes from a range of disparate funding sources making planning difficult. The increased costs faced by many local councils involved in providing integrated programs jeopardises the sustainability of not only existing outside-school-hours care, but the development of new programs in areas of unmet need. The ACD report documents the inability of current integrated outside-school-hours programs to adequately cater for the needs of adolescents with disabilities (Mathews 2009).

The ACD report highlights the problems that arise when adolescents with a disability are integrated into mainstream programs which are targeted at primary school-aged children. Primary schools that deliver mainstream programs lack the expertise, facilities, resources and appropriate staffing levels to successfully integrate adolescents with a significant level of disability. Disengaged adolescents with a disability who exhibit behaviours of concern have been excluded or expelled from outside-school-hours care programs.

Carers Victoria advocates the need for specialised government funding for outside-school-hours care programs for adolescents with a disability. It is essential that funding is accompanied by transparent and clearly articulated lines of accountability between levels of government. Or, alternatively, that funding is provided to one level of government that is made responsible for the funding and development of educational and recreational opportunities for adolescents with disabilities. Either arrangement will enable parents with caring responsibilities to have greater attachment to the labour market.

The transition of parents of children without disabilities from work, to care and back again, is supported by a comprehensive range of interlinked government policies which recognise the value of child-rearing. These policies cover income security provisions, allowances and tax rebates, including: Paid Parental Leave (from 1 January 2011), the Baby Bonus, Family Tax Benefit Part A and B, Parenting Payment, Child Care Benefit and the Child Care Rebate.

The protection and recognition of parents with child-rearing responsibilities through the National Employment Standards came into effect in January 2010. These provisions ensure parents are increasingly able to balance their child care responsibilities with their workforce participation. They provide parents with the right to request flexible work arrangements to accommodate their family responsibilities. These provisions will be available to all parents, including parents of a child with a disability up to the age of 18. However, they are not accompanied by any government commitment to increase funding for outside-school-hours care to ensure that parents of adolescents with a disability can access appropriate programs. In addition, there are no provisions for parents of an

adult with a disability to request flexible work arrangements, and no investment in the development of vacation and outside-centre-hours care programs for adolescents and adults with disabilities. These parents are additionally disadvantaged, as they receive no assistance with the costs of care.

Combining paid work with care responsibilities is more difficult for parents of people with a disability. There is no guaranteed access to adolescent or adult care to support their participation in employment. In addition, there is no equivalent to the Child Care Benefit for dependent adolescents and adults with disability. This creates an inequitable arrangement between individuals and families with varying care responsibilities. Gordon Grant has argued:

As the (disabled child) grows into adulthood the focus of professional attention, rightly or wrongly, is much more with the disabled adult rather than the family... Whether this planned or unintended withdrawal of services over the life course leads to heightened interdependence between older families and disabled adults who still live at home remains open to empirical study (Grant 2003:98).

5 Consultations with carers

5.1 Objectives

Ways to Work builds on the growing literature about care and workforce participation. It explores the needs and preferences of 21 parent carers of adults with an intellectual disability. It details their preference to work, the barriers they face and the ways in which the service system could better support them to balance paid work with unpaid care.

The key focus of this study was:

1. How do family carers of workforce age currently use programs and services to support their workforce participation?

- What is known about the availability, accessibility, affordability and quality of alternative care programs?

2. What are the needs and preferences of family carers of workforce age who are not currently participating in the paid workforce but who would like to do so?

- What strategies would best support them to re-enter paid employment?

5.2 Methodology

A triangular methodology was used in this study to generate both qualitative and quantitative data; to provide an opportunity for explanatory enquiry; and to ensure that the research questions accurately captured the complexity of the issues. The study combined open, closed and scaled questions.

Throughout this report, names have been altered to protect the privacy of the both the carers and the people for whom they care.

The Household Income and Labour Dynamics in Australia (HILDA) Wave 6 questions were used as a basis for the survey questions in order to ensure definitional consistency and to gather data that could be viewed against larger qualitative studies (such as Nepal 2009).

5.2.1 Data collection

The study comprised seven sections reflecting three discrete areas:

- Sections 1 and 2 focused on carers currently participating in the workforce and their experience of combining paid work with caring;
- Sections 3 to 5 focused on carers not currently participating in the paid workforce; the services that would support them re-entering the paid workforce and their past experience of combining paid work with caring for a family member with a disability;
- Section 6 focused on the family member requiring care; and
- Section 7 focused on the carer respondent.

Each of the seven sections provided participants with an opportunity to provide relevant information which was not directly sought by the questions.

An understanding of the potentially invasive nature of research and a desire for participants to be in control of their own story guided the approach of the researcher. For this reason not all questions have a full response rate.

5.2.2 Sampling strategy

The survey instrument was trialled on two members of Carers Victoria who fit the participant profile. Their suggestions were incorporated into the design of final study. A search of the Carers Victoria membership database was conducted to draw out a list of members of working age who are caring for an adult with intellectual disability and had previously agreed to participate in research studies.

Eighty potential participants were selected from this list, with the aim of getting a mixed sample that included male and female carers, carers from culturally and linguistically diverse backgrounds, and remote, rural and urban carers. Letters were sent out inviting people to take part, together with a copy of the Plain Language Statement. Participants also received information outlining the various ways they could participate, including via telephone interviews or through electronic/hard copy surveys. The invitation to participate was followed up with a phone call the following week.

A response rate of 16.8% was achieved using this strategy. The study was completed by 21 Carers Victoria members between January and March of 2009:

- eighteen surveys were conducted by telephone, taking on average 47 minutes to complete;
- two surveys were returned via email, and took the respondents on average 80 minutes to complete; and
- one survey was returned by post but without an indication of the time taken to complete it.

5.2.3 Limitations

The sampling strategy yielded 21 respondents:

- all of the respondents were women;
- three were from culturally and linguistically diverse (CALD) backgrounds, one of whom was born outside Australia; and
- four respondents lived in regional Victoria.

The lack of participation by male carers, and the under-representation of CALD carers limits the representativeness of the study.

6 Results of the consultation

6.1 Carer participants

- Twenty-one female carers participated in the study.
- Twenty are mothers (one adoptive), and one participant is caring for her niece.
- Twenty identified as primary carers, and one respondent '*shares the care with her husband*'.
- Eleven respondents are sole carers. Of these, ten live in a caring dyad.
- Ten respondents are partnered. Three respondents reported receiving a very good level of support from their partners.
- Five respondents reported that siblings of the adult with a disability also provide care.
- Respondents ranged in age from 43 to 64 years with an average age of 55.

6.2 The people for whom they care

Sixteen adult offspring require supervision most of the time. The respondents described the nature of the disability of their offspring as follows.

Respondent 1 - *Autism, intellectual disability, and some mental problems.*

Respondent 2 - *Mild intellectual disability, epilepsy, motor delay, depression and anxiety. Sally needs to sleep during the day which makes using services and programs difficult.*

Respondent 3 - *Autism spectrum disorder, mild to moderate intellectual disability, and controlled epilepsy.*

Respondent 4 - *Autism with intellectual disability and undiagnosed muscle disease. He has low muscle bulk that damages very easily.*

Respondent 5 - *Severe intellectual disability.*

Respondent 6 - *Uncontrolled epilepsy, and developmental delay – the prognosis is that she will get worse.*

Respondent 7 - *Intellectual disability or Global Developmental Delay.*

Respondent 8 - *Mild intellectual disability and personality disorder, autism and obsessive compulsive disorder.*

Respondent 9 - *Intellectual disability with obsessive compulsive disorder.*

Respondent 10 - *Cerebral palsy, intellectual disability, visual impairment, and behavioural problems.*

Respondent 11 - *Epilepsy, autism and intellectual disability. Scar tissue on both sides of the brain, acquired brain injury.*

Respondent 12 - *Sleep apnoea leaves him debilitated. He has non-specific psycho-motor retardation and no speech. He won't walk distances.*

Respondent 13 - *Uncontrolled epilepsy; she has three types of seizures.*

Respondent 14 - *Global Developmental Delay and autism – she can't see colours, and is unable to keep herself occupied.*

Respondent 15 - *Developmental delay; severe mental impairment and autism. He is non-verbal.*

Respondent 16 - *No particular diagnosis; she is mentally retarded.*

Respondent 17 - *Down syndrome and autism with a severe intellectual disability.*

Respondent 18 - *Acquired brain injury, epilepsy, an autoimmune disorder.*

Respondent 19 - *Autism spectrum disorder and mild intellectual disability. She has poor verbal skills.*

Respondent 20 - *Mild intellectual disability.*

Respondent 21 - *Mild intellectual disability with an episodic psychiatric condition which can have severe effects.*

6.3 The workforce participation of the carers

6.3.1 Table 1. Working carers

Highest qualification	Current position	Basis of employment	Range of hours worked p/wk	Preferred number of hours	Household	Hours worked p/w by partner	Disability of adult offspring
Bachelors degree	Maths teacher	Permanent full-time	40 < 48	32 < 40	Family of 5	>50	Severe
Year 9	Technical site services	Permanent full-time	32 < 40	32 < 40	Caring dyad	–	Moderate
Bachelors degree	Adult Teacher/trainer	Part-time	24 < 32	16 < 24	Family of 5	32 < 40	Moderate / severe
Masters of Nursing	Case manager, CAPS Packages	Part-time	24 < 32	24 < 32	Family of 3	32 < 40	Severe
Year 10	Personal assistant	Part-time	16 < 24	24 < 32	Caring dyad	–	Mild
Post Graduate Midwifery	Nurse and Midwife	Part-time	16 < 24	8 < 15	Family of 7	> 48	Severe
Business college	Office manager	Part-time	24 < 32	16 < 24	Family of 5	60	Mild / moderate
Certificate IV in Disability studies	Disability support worker	Part-time	24 < 32	16 < 24	Offspring lives semi-independently	40 < 48	Mild
Registered nurse Div. 2.	Disability support worker	Casual	16 < 24	0 < 8	Offspring lives semi-independently	–	Moderate
Masters of Education	Academic research assistant	Casual	24 < 32	16 < 32	Family of 3	–	Mild
Certificate III in Disability studies	Disability accommodation support officer	Casual	16 < 24	24 < 32	Caring dyad	–	Mild / moderate

Table 1. Working carers: 11 of the 21 study participants are in paid employment.

Case study – Tracey and Louise

Tracey is a 54-year-old sole parent living in a caring dyad with her 36-year-old daughter Louise who has a moderate intellectual disability. Louise attends a day service and the Care to Work program at Karingal.* Tracey says it meets the family's needs:

Well ... I can't speak highly enough of them... Karingal run a Care to Work program for older and working mothers – it's like before and after school care.

Tracey has a permanent full-time position in a government department providing technical site services. She left school after completing Year Nine and has been fortunate to have '*learnt on the job*.' Tracey is open with her manager and colleagues about her caring role and describes their response as '*wonderful – they don't know how I do it*.'

Tracey is aware of legislation that supports people with caring responsibilities in the workplace. She has access to family-friendly work arrangements and has used her leave entitlements under these arrangements to help her juggle caring and work '*many times*' commenting that '*they do work*'. She describes combining care and work as '*very tiring*' and says that caring affects her paid work '*all of the time*'. She has considered giving up work many times due to the demands of caring. Tracey finds getting respite outside of her working hours difficult:

The Karingal model is really good but sometimes it [working and caring] does get on top of me. I would like more time apart to lead a more 'normal' life.

* See case study (page 37), Karingal's Care to Work program, for an explanation of the program.

6.3.2 Carer profiles: full-time employees

Two of the 21 respondents were in full-time permanent jobs. One worked 40 hours or more per week as a secondary teacher but would prefer to work less. Her husband is also employed full-time in secondary education and they share the care of their son.

The day service that he goes to is in synch with the school holidays and I am a teacher. My husband starts late. After school my other son looks after him.

Tracey is the other participant in full-time employment. See case study, *Tracey and Louise*.

6.3.3 Carer profiles: part-time or casual employees

Six respondents are employed part-time, and three are employed on a part-time/casual basis. Only one respondent who works part-time reported having a real sense of control over her working life. She has post-secondary qualifications and combines teaching in the TAFE sector with sessional work for a variety of Registered Training Organisations:

I chose not to work until my youngest (not disabled) was at school. From then on I have always worked part-time from choice.

Care responsibilities are the reason most participants gave for not working full-time. With limited access to training and promotion, study respondents are concentrated in low-paid jobs. Seven of the 21 respondents are working or have worked in the disability field where being a carer is regarded as relevant experience or a non-issue by employers.

I work in the disability field; it's very understanding.

My care responsibilities were spoken about at the interview – I was working in the disability field, they were welcoming of employing a carer.

There are a lot of people who do homecare who have a family member with a disability.

While the disability field lends itself to part-time and casual employment, it is poorly paid; physically demanding; has limited career progression; and provides little opportunity to save for retirement. It is generally undervalued by society and frequently carried out in people's homes rather than in workplaces. It offers limited opportunity for social interaction and the building of networks.

Part-time and casual work provides only marginal attachment to the labour force while full-time employment provides greater stability and the ability to effectively plan and manage resources on a longer term basis. When study participants were asked how many hours they would choose to work each week, those who were not working and those who were working in part-time and casual positions expressed a desire to work between 16 and 24 hours per week. Several indicated they were seeking employment between the hours of 10 am and 2 pm on weekdays. This demonstrates the constrained choices that individual carers make due to the lack of out-of-hours care or the lack of any appropriate alternative care arrangement. In addition, the respondents' choices relating to greater workforce participation are constrained by the current income support arrangements. As one carer put it:

I work my hours around continuing to be eligible for the Carer Payment.

Low-paid, casualised jobs provide few opportunities for training and career advancement and rarely lead to full-time jobs. A report by the Organisation for Economic Cooperation and Development (OECD) suggests that the flow of the casual labour force is often between no pay, low pay and back again (Ziguras et al. 2004). This is the experience of many study participants. Australian research supports this finding. A recent working paper released by the Centre for Full Employment and Equity (CoffEE) found that 'casual employment does lock in workers' (Welters and Mitchell 2009:11). This supports the finding of previous studies that there is 'no conclusive evidence that casual employment functions as a stepping stone towards non-casual employment' (Welters and Mitchell 2009:3).

6.3.4 The experiences of combining paid work with caring

Participants were asked about their experience of combining paid work with caring:

I couldn't work until we got Home First. I have been limited to working when other family members are home.

It is very difficult. My husband and I broke up eight years ago. I had to go part-time because that was all I could manage. There are no after school programs for kids with special needs.

The biggest part is emotional exhaustion. I first started working when Jason was seven years old. I found it really good to have access to a life outside of caring and disability. I worked full-time for a while but Jason went backwards, so now I do casual work and get shifts to suit Jason. It's a juggling act.

For the carers surveyed, combining paid work with unpaid caring requires constant juggling and the outcome for most has been 'exhaustion.' A number of studies have found that primary carers consistently work below their level of qualification. In order to address these disadvantages carers need more understanding workplaces and access to more flexible work arrangements throughout the life course (TOCC 2007; Lymer, Percival & Harding 2006).

For the majority of respondents, caring affected their paid work all of the time. Ten of the 11 carers in paid work had declined training or a promotion because of the demands of caring. Nine had considered giving up their current job due to the demands of caring; several '*many times.*' Most respondents were working in the role that they were qualified for although one respondent reported that she had '*always worked below her level of qualification.*' Most felt that they would have undertaken more training and gained higher qualifications and more senior jobs had they not been primary carers. One reported withdrawing from her Doctorate, and two have withdrawn from a Masters degree. The following comments are typical:

I couldn't pursue the career I wanted. Mathew requires hospital level care. I dropped out of university when he became sick and have only ever worked part-time since.

I could have done a lot better at work if I was not a carer.

6.3.5 Table 2. Carers not currently working but who would like to

Highest Qualification	Preferred basis of employment	Number of hours carers would like to work p/w	Household	Partner working?	Hours worked p/w by partner	Disability of adult offspring
Post Grad. Diploma in Legal Studies	Full-time	40 < 48	Caring dyad	-	-	Severe
Year 12	Permanent part-time	24 < 32	Caring dyad	-	-	Moderate
Trade certificate	Permanent part-time	16 < 24	Offspring lives semi-independently	No	-	Moderate/severe
Certificate 11 in Customer Service	Permanent part-time	16 < 24	Family of 4	Yes	40 < 48	Moderate
Bachelors Degree	Permanent part-time	16 < 24	Family of 3: 1 adult, 2 children	-	-	Severe
Year 12	Permanent part-time	8 < 16	Caring dyad	-	-	Moderate
Year 10	Permanent part-time	8 < 16	Caring dyad	-	-	Moderate

Table 2. Carers not currently working but who would like to work: seven out of 21 study participants are not in paid employment, but would like to be.

6.3.6 Carer profiles: unemployed

Of the 21 respondents surveyed, ten respondents are not currently in paid employment. Seven described themselves as looking after a person with an illness or person with a disability. All seven cited inadequate support services for their children with disability as the main reason they are not working. They would all like to return to paid work if they could afford to rely on and trust services to adequately support their family member with a disability.

Respondents who were not currently working expressed a variety of concerns about re-entering the workforce. These concerns included the impact it would have on their health; lack of confidence after a substantial absence from the workforce; the cost of substitute care; and the impact it would have on their income support eligibility. One respondent lamented her 'loss of confidence, loss of networks, and loss of skills.'

Several participants had experienced their caring role as a barrier to employment. One made the observation that:

When prospective employers find out that I have a son with a disability they say "you would be taking time off" and the awful truth is that I would because there is not the required back-up.

6.3.7 The Carer Payment

Receipt of Carer Payment distorts the workforce attachment of carers. The combined effects of the 25-hour rule and Effective Marginal Tax Rates (EMTR's) for carers in receipt of the Payment frequently govern the choices carers make about how many hours they work and on what basis.

The 25-hour rule states that carers cannot work, train or study for more than 25 hours per week (including travel time) and continue to be eligible for the Carer Payment.

Case Study – Kerry and Jill

Kerry is a sole parent carer in her mid 40s who suffers from depression. She lives in a caring dyad in social housing with her 20-year-old daughter. Jill has cerebral palsy, intellectual disability, visual impairment and behavioural problems.

Jill is totally dependent for everything. She is in nappies and nasogastrically fed.

Jill transitioned from special school to an adult day service when she turned 18. Kerry reflects on what this transition has meant for Jill:

She has deteriorated. She doesn't get therapy anymore. No occupational therapy, no speech therapy the things that she had everyday at school.

When asked about her hopes for Jill's future, Kerry responded:

I don't have any. Isn't that horrible? You can't think about the future. There is just this. What we are doing now. I see it as me and Jill doing every day like we are doing.

Kerry stopped working when Jill was born and is in receipt of the Carer Payment. She has been unable to re-enter the paid workforce due to her caring responsibilities and inadequate access to support services.

Kerry has undertaken a Post Graduate Diploma of Legal Skills and Ethics over the last 10 years and was due to qualify as a solicitor two weeks after our interview. In order to be able to practice as a solicitor, Kerry is required to complete two years supervised employment in a legal practice.

The prospect of full-time employment brings with it potential social and economic benefits:

I need to work for my own mental health, to get out of my current cycle... I need a wheelchair van for Jill – I can't get a loan without a full-time job.

A transition from caring to work involves considerable risks for Kerry and Jill. Kerry is concerned about accounting for the 20-year gap in her resume:

You get in such a rut. You lose other skills being out of the workforce. People are

going to ask me: "why haven't you been working for 20 years?"

There is also the issue of substitute care for Jill who currently attends an adult day centre. The centre hours are from 9 am to 3 pm each day which provides difficulties for Kerry in seeking full-time employment. Kerry also *'has problems during vacations'*.

We have no family around so it is just impossible. What will I do if Jill is sick? What will I do before and after work?

Kerry expressed a preference for:

Day services which go an extra three or four hours a day, or after centre hours care with transport there and transport home. It would be easier to stay at the day service but with different staff... A program with more therapists involved. One with more activities like swimming ... We may also need before centre care or in-home care. My preference is out-of-home care, to get her out mixing with other people.

The program would need to provide transport as:

I wouldn't put Jill in a taxi by herself.

Kerry explains the particular risks she faces gaining full-time employment and leaving the Carer Payment:

Getting an income means I get cut off the Carers Payment and lose the Health Care Card. I live in Ministry housing so I will be paying market rent ... Would working be worth it if I have to pay someone else to look after Jill full-time?

For Kerry there is little apparent reward for her decade of study. Barriers in the income support system and the unavailability of support services mean that taking up a position in a legal firm may be impossible.

I'm convinced that the government wants me to stay home and look after Jill. That's their cheap option!

Study participants who were working on a casual or part-time basis and carers who were not currently working but expressed desire to, would prefer to limit their prospective workforce participation to between 16 and 24 hours per week, to ensure they retain eligibility for Carer Payment and the accompanying Health Care Card, which provides access to a range of benefits and concessions.

The Carer Payment is paid at the same rate and subject to the same income and assets tests as other Commonwealth Pensions. These Payments are reduced by forty cents in the dollar for every dollar earned over \$132.00 per fortnight. The actual value of the payment is further reduced when income tax and the costs associated with working are deducted. This quickly reduces the financial benefits of commencing or increasing workforce participation. A NATSEM study of Effective Marginal Tax Rates (NATSEM 2006) showed that it is often those on the lowest incomes who are most disadvantaged by the interactions between income support and taxation.

Years of being unable to participate in the workplace may result in carers needing subsidised training to increase their prospects of gaining employment. Recipients of the Carer Payment can generate working credits and gain eligibility for various small programs administered by Centrelink. This includes the Pensioner Education Supplement and Fares Allowance, career planning and employment preparation. None of the carers surveyed were aware of these programs.

Carers in receipt of the Carer Payment are not eligible for the training provided for Newstart Allowance recipients. This training is administered by the Department of Education, Employment and Workplace Relations (DEEWR) through the Productivity Places Program (PPP). Under the Skilling

Australia for the Future initiative, the Australian Government has committed to deliver 711,000 (PPP) training places over five years. These training places are being delivered in an 'industry driven system, ensuring that training is more responsive to the needs of businesses and participants (DEEWR, 2009).' Of the places, 392,000 will be allocated to existing workers wanting to gain or upgrade their skills, and 319,000 (including 20,000 Structural Adjustment Places) will be allocated to job seekers.

Carers Victoria recommends that Carer Payment recipients be given priority access to PPP places to ensure they have the opportunity to gain the skills they require to re-enter the labour market or to upgrade their skills to secure more permanent employment. As part of this program, a number of places could be set aside for Carer Payment recipients, similar to the arrangements as part of the Economic Stimulus Strategy, which earmarked 10,000 PPP places for newly retrenched workers.

To ensure that carers can balance their caring responsibilities with the demands of training, it is important that training is delivered in a flexible way. Following completion of the training program, carers should be provided with appropriate assistance to enable them to undertake job-search activities. Whilst training and job-search support would be of interest to many carers, it is important that no additional participation obligations or requirements are applied to these activities and supports. Carers unable to find appropriate employment following completion of training and associated job-search supports should not face any penalties.

6.3.8 The impact of carers' health on workforce participation

The health of carers has a considerable impact on their ability to maintain employment. Several studies have found that carers have an increased likelihood of developing serious health conditions due to their caring role. This presents significant barriers to finding and sustaining meaningful employment. Many of the survey participants rated their health as fair or good, but when asked about health conditions that impacted on their caring role and their ability to participate in the workforce, the most common health concerns were:

- psychological conditions - such as extreme stress, anxiety and depression; and
- physical conditions - such as arthritis, back and shoulder pain and obesity-related health conditions.

Adequate supports, including flexible and regular respite, allow carers to maintain their own health which is vital to maintaining an attachment to the workforce. Inadequate supports lead to early withdrawal from the workforce and increased dependency on both the Disability Support Pension and the Age Pension.

Addressing the disincentives for carers to work

Recommendation 1

That Commonwealth Government remove the current disincentives for carers in receipt of income support payments to combine informal care and paid work. This can be addressed in the context of its response to Australia's Future Tax System Review.

- **Particular attention should be given to examining the impact that effective marginal tax rates, the 25-hour rule, and eligibility for the Health Carer Card have on the labour force participation of carers.**

Recommendation 2

That the Commonwealth Government, through the Department of Education, Employment, and Workplace Relations (DEEWR) guarantees that Carer Payment recipients have access to training to maintain, develop and increase their workskills. This will assist them to enter or re-enter the labour force when they are able to do so.

- **It is essential that the Productivity Places Program allocates priority places to carers.**
- **It is essential that Centrelink determines eligibility and refers new Carer Payment recipients and renewed recipients to the Productivity Places Program.**

6.3.9 *The importance of a carer-friendly workplace*

All study participants who were in paid employment were open with their first-line managers and colleagues about their caring roles. The response of managers and colleagues ranged from being fairly supportive to totally supportive. Respondents indicated they had moved around the labour market until they found work in a field that was supportive of their caring role and provided flexible work arrangements. This is a rather tenuous arrangement as it relies on the continuing goodwill of their manager and that the manager remains in place. One carer explained: *'I'm lucky that I have a supportive workplace'*.

Carers' labour force engagement would be better supported by extending the National Employment Standards to ensure the right to request flexible work arrangements is available to carers of an adult with a disability. Greater employer and employee awareness of the protective functions of the Victorian Equal Opportunity Amendment (Family Responsibilities) Act (2008) may also assist parent carers who experience workplace discrimination.

There is a need to educate employers in the benefits of offering their employees greater flexibility in work arrangements. This includes leave provisions, such as 48/52; working from home; job-sharing; and family-friendly care rooms on-site. Employers will gain greater competitiveness in a changing labour market (with an ageing workforce and a skills shortage looming) and the ability to retain skilled staff. Flexible work arrangements have the ability to retain and attract employees with child or adult care responsibilities, those managing chronic illnesses, individuals who are balancing work and study and employees who are stepping down to retirement.

The government has a role to play in working collaboratively with employers to develop incentives to modernise the Australian workplace. For example, the government could promote best practice in this area by introducing programs similar to the Equal Opportunity for Women in the Workplace Agency (EOWA) *Employer of Choice Awards*.

6.3.10 *The outcome of part-time and casual work for carers*

Carerfriendly workplace practices, including flexible work hours, job sharing, job redesign, working at home, 48/52, and flexible use of the telephone were rated as important by study respondents who were currently participating in paid work. All respondents who had access to any form of paid leave reported using it to meet the demands of their caring role. Access to carer friendly leave arrangements is considered very important to carers who would like to re-enter the workforce, potentially because five of the seven of

these carers are living in caring dyads. They have no readily accessible back-up care for illness or emergencies.

Paradoxically, three carers work on a casual basis in order to accommodate their caring responsibilities. In doing so, they are excluded from any family friendly leave provisions. For one respondent this results in periods of unemployment:

I am a part-time university researcher on a short-term contract. I have deliberately chosen this role as it best fits in with my caring role. I work both in schools and at home according to the needs of the research project. The availability of such work is limited, therefore I have had considerable periods of unemployment.

For participants in this study, workforce participation and the desire to work are motivated by the drive to meet very immediate needs: a roof over their head; a wheelchair van for a daughter who has mobility impairment; and for a rural carer, a reliable car to transport a son with low muscle bulk to and from services. For the majority of the respondents the interview was about access to *jobs*. Few had much hope left for a *career* and the benefits one may provide.

Carers in the workplace

Recommendation 3

That Commonwealth and State Governments, their agencies and peak employer bodies actively promote carer friendly workplace practices.

Recommendation 4

That the Commonwealth Government amend Section 65(1) of the *Fair Work Act 2009* to extend the right to request flexible working arrangements to all family carers across the life course. This will include those caring for adults with a disability or chronic illness and those caring for adults who are frail and ageing. It would ensure equitable support for all caring families.

6.3.11 Carer profiles: retired early

Of the three respondents who had 'retired' from paid work early; two were in poor health, two had multiple caring roles and two lived in a caring dyad. Parents of people with an intellectual disability have a significantly different experience of retirement from their peers who do not have caring responsibilities. They continue to provide unpaid care to their adult offspring.

6.3.12 Table 3. Carers no longer seeking work

Reason that you are no longer seeking work	Age	Age at retirement	Household	Partner working?	Hours worked p/w by partner	Disability of adult offspring
Also cares for her mother	60	59	Caring dyad	–	–	Mild
Left the workforce due to health issues	63	55	Family of 3	Yes	Not known	Moderate
Also cares for another son now in supported accommodation	59	58	Caring dyad	–	–	Severe

Table 3. Carers no longer seeking work: three participants have retired early from paid employment.

6.4 The services carers used to support participation in employment

There are three categories of services that have the potential to support the workforce participation of caring families where an adult member has an intellectual disability. These are disability services; Home and Community Care (HACC) services and respite and recreation services. The study uncovered only one service specifically designed to support the workplace participation of carers.

Of the 21 carers surveyed, 19 cared for adults who were regularly participating in programs delivered by disability services:

- fifteen attended an adult day service;
- two adult offspring were attending a business service;
- one combined an outreach service with part-time employment; and
- one accessed only 12 hours of service per week.

The daughters of two respondents were not using any services:

- one was in supported employment at her mother's workplace; and
- one was unemployed following completion of a TAFE course in 2008.

Adult day services are funded to assist a person who is over 16 years who is 'disabled' as defined by the *Disability Act 2006*. They provide:

- a minimum of 30 hours attendance per week (6 hours per day);
- involvement in structured program activities for a minimum of 22.5 hours per week (4.5 structured program hours per day);
- programs for 45 weeks per year (excluding public holidays and three program development days); and
- facilitation of transport to and from the service, using participants' Mobility Allowance (DHS 2008b).

6.5 Limitations of existing services

6.5.1 Disability services: limited hours

Caring families overwhelmingly reported that the length of the 'day' for adults with a disability across all adult disability services is too short. Many primary carers are confined to working or looking for work within these limited service hours.

6.5.2 Lack of availability of before and after day service care

Ten out of 13 respondents rated finding appropriate supervision for their family member before and after usual service hours as a problem or very much a problem. Only one had access to an ongoing substitute care program. Others felt that *'the costs of an in home carer for the time before and after day placement are prohibitive.'*

6.5.3 No day programs during vacation periods

Respondents also encountered difficulties during day service holidays. Most respondents reported finding suitable alternative care arrangements as a problem or very much a

problem. A typical comment was: *'finding things for him to do during centre holidays is very difficult.'*

The closure of centres during holiday periods leads to employed carers having to juggle care arrangements between themselves, other family members, friends and service providers. Juggling multiple services was rated as a problem or very much a problem by 12 of 14 respondents. Several participants reported applying each term for a place in a council recreation program. They often find themselves on *'impossibly long waiting lists.'*

6.5.4 HACC services

The HACC program aims to 'provide a comprehensive, coordinated and integrated range of basic maintenance and support services for frail aged people, people with disability and their carers' (DoHA 2009:1). Eligibility for HACC services does not depend on age or income. However, not all those eligible are able to receive an immediate service (DHS 2009). The Victorian Government has developed priority guidelines to manage demand for HACC services. Fifty per cent of HACC users have a carer and 'the role of the HACC program is to find the most effective way of supporting informal caregiving' (DHS 2008a:8). The Victorian priority guidelines stipulate that:

If a carer is available consider how providing care is impacting on their physical and emotional wellbeing. Is providing care and social support having a major impact (select high), moderate impact (select medium), or minimal impact (select low)? The high column would be selected if it were unlikely that the carer would be able to continue caring without some additional assistance. Consider carers' own health and social support network. (Buckley et al. 2007:10)

These guidelines provide a framework for HACC services to support carers to continue to provide unpaid informal care. They do little to support carers to participate in activities outside the home. This small study supports the findings of larger studies (Nepal 2009; Edwards et al. 2008; Cummins et al. 2007) that workforce exclusion due to the demands of caring has a detrimental effect on carers' physical and emotional wellbeing. Conversely, participants in this study reported that workforce engagement had a positive impact on their economic and social wellbeing.

Study participants had inconsistent experiences of using the HACC program to support their workforce participation. Several were using HACC services to support their employment while others had been explicitly told that it could not be used for this. These experiences reflect an inconsistency in the Victorian HACC Program Manual 2003:

The domestic and financial circumstances of individual carers may also have to be taken into account, as it could be essential that a carer remain in employment (DHS 2003:62).

Later in the same manual it states:

Respite (home and community) is not available to provide care while the usual carer undertakes paid employment or unpaid volunteer work (DHS 2003:130).

The carers surveyed experienced this inconsistency, as the HACC program constructs carers' workforce participation as a privilege.

Council say that respite is not for me to be able to go to work.

Respite hours are not to be used for work.

I can't plan around council carers as they can't commit until the day before.

It is extremely difficult to be in the paid workforce with confidence that it will be a long term arrangement. If a [paid] carer doesn't turn up I can't go to work. Work is seen as more of a privilege than a right. I have no super, no career.

I have given up trying to get HACC services. It's too hard. There is an assumption by council that his siblings will fill the gap.

The HACC services used by the carers surveyed include personal care, in-home respite and out-of-home respite. Carers reported problems with the limited hours available and worker training, turnover, and unreliability.

The council needs better service; there are not enough care workers or places. We spend much of our respite hours training carers. He finds a change of respite worker very upsetting.

Hazel lives 90 steps away in a flat. She had 18 people come through to provide support over a two year period. She loves the company, but Hazel understands them as friends. When they change jobs and go Hazel is devastated...constant grief. The support workers have introduced Hazel to their entire family. She becomes part of their family and then they change jobs and she is devastated.

The carers who participated in this study were all determined to ensure that their adult offspring have a good quality of life, founded on good quality of care. Many participants reported having left a job on one or more occasion when substitute care arrangements broke down or were felt to be inadequate. One participant reported leaving work following her divorce in order to resume the role of full-time carer.

6.5.5 Respite services

Respite is a difficult issue for participant carers. A variety of respite programs are used by study participants including:

- in-home respite provided by a range of NGOs;
- out-of-home respite provided by a range of NGOs;
- Yooralla respite hours;
- DHS respite houses;
- Council holiday recreation programs;
- interchange recreation programs;
- camps provided by various NGOs during holidays; and
- Karingal's Care to Work program.

Access to respite is unreliable and waiting lists are long. In some instances the respondent's adult offspring did not want to use a service:

The difficulty I have is to get Jill to go to programs. She has a mind of her own and often refuses to participate. There are things that she could be involved in but she chooses not to be.

Nine carers reported that a variety of respite service providers did not define participation in work as 'a break from caring'. Only two participants reported that they had been offered respite to support their workforce participation.

Respite services see their role as supporting "time out" – not work.

I can't tell them that I'm going to work. I can't get respite if I'm using it as a "babysitting service". The attitude of service providers needs to change. They need to understand that I need to work.

I tried to book her on outings on the days that I worked or I used family or asked her father. ... A worker from Interchange told me that "Interchange was for respite, not so that I could go to work".

The attitude is that if a carer works that is a "privilege". They don't seem to have the same rights as the rest of the population. Can't work equals poverty.

In order for carers to commit to workforce participation they need access to regular ongoing alternative activities for their offspring with a disability. Study respondents in general felt that work provided them with a break from caring – an important respite effect. Workforce participation supports the maintenance of an identity beyond being a carer.

Employed carers made the following comments:

Work provides me with respite and interaction with a bit of normality plus extra income.

You get away from caring. You meet different people. You move in different circles. It's important for self esteem. Work takes you away from other issues ... the carers who cope the best are the ones who have a life outside caring.

I need to feel good about myself and I don't. I used to feel okay when I had a job and I had money coming in. All I can say is negative things: I don't have a partner, I don't have a job, I just want to improve myself and for me and Eileen to be happy and have a sense of purpose.

There are substantial definitional issues with regard to respite services. Respite is often explained to families as the opportunity to 'take a break' from caring. The 'break' is most often being defined by service providers and rarely by caring families. One respondent explains:

I have aged parents who I support. Respite services would not give me respite to care for my aged parents as they said "it wasn't time out".

Eighteen respondents reported that they did not have access to enough respite at the right time. The following comments are indicative of the frustration expressed:

The waiting list on the local respite house is not moving – there is no point being on it.

DHS are using up respite centres for permanent places and stopping people getting respite in holiday periods.

I really don't think that there is enough respite available. Janice gets three hours a week and there is no more available.

Carers who participated in the study currently cobble together a variety of services to support their participation in employment. In general, they limit their employment to the length of the day program attended by their son or daughter. Access to appropriate supervision before and after day service hours is problematic, as is the shortage of alternative activities during vacation periods. Limits to the availability and continuity of the HACC program combined with a lack of clarity in HACC program guidelines about supporting carers in employment create barriers for carers' workforce participation. Carer respite programs are similarly limited.

Services to support carers to participate in employment

Recommendation 5

That the Commonwealth and State Governments amend policy and funding guidelines for respite programs and the Home and Community Care (HACC) Program, to recognise and support greater employment participation for carers. The availability of regular, predictable and ongoing respite hours is vital for caring families and will underpin the work force participation of carers.

6.6 The preferences expressed by carers about needed service models

6.6.1 Access to outside-centre-hours care

The majority of respondents would like the hours of day service currently provided to them lengthened. They expressed a preference for a combination of the following two models of service:

1. A structured activity program operating before and after day service between 8 am to 9 am and from 3 pm to 6 pm.
2. Access to additional in-home respite before and after day service and during service vacations.

Many felt that the most practical way to provide a structured program would be to have different staff providing the service at the existing locations:

After school type of care with transport there and transport home. It would be easier to stay at the day service but with different staff.

Day centres open from 6.30 am until 6.30 pm and available on an occasional basis.

I would need the same kind of care that I get for my granddaughter – daycare available between 6.30 am and 6.30 pm out of home, or a carer who is like part of the family. It needs to be run along the same lines as before and after school care in familiar surroundings... Programs should start at 8 am like a normal workforce and run through until 6 pm, with the option of doing half days. Flexibility is the key.

We need more respite in the holidays. We need out-of-home respite. Having different staff come into the day centre would be good. All the respite places we want to access to during vacations are booked up. There are not enough places. We need more services.

Providing out-of-home respite to adults with an intellectual disability is a complex task that requires a suitable venue, trained staff and a budgetary allocation that ensures people with high care needs can participate. It also requires access to appropriate transport. The provision of out-of-centre hours and vacation care would ensure that appropriate care is provided to support families as a whole, rather than only the adult with a disability.

Some participants expressed a preference for the provision of in-home respite before and after usual service hours:

I would prefer funding for in-home support – so long as it functions. People need to be better qualified.

More respite care – in-home.

Before and after care, or workers who come to my home before and after program hours.

Case Study – Karingal’s Care to Work program

Karingal is a large provider of adult disability and aged care services in the Barwon South West Region. It has eight sites around Geelong.

The *Care to Work* program was started in response to demand by families who could not get HACC services before and after usual day service hours. Karingal was aware of bus journeys of up to 1.5 hours to and from day service being used as ‘informal respite’ by some families in need.

The *Care to Work* program provides respite to caring families who are working, looking for work or providing care to other family members. It balances the needs of carers for substitute care for their offspring with the needs of adolescents and adults with intellectual disability. The program provides a combination of activities as well as community participation and relaxation. It is held at a different site each afternoon and activities include visiting Geelong, swimming, bowling, and watching television. The cost is five dollars a day plus consumables. Participation is flexible, and they can provide service before 9 am if there is sufficient demand. The great strength of *Care to Work* is that it provides respite at the time families want and need it.

The *Care to Work* program is open to people who are aged 16 years and over. Clients use their usual form of transport to get to the program each afternoon, which is usually covered by their mobility allowance, but it does not provide transport home. According to the program manager, the lack of transport home in the evenings means that many caring families who would benefit greatly from the program are unable to access it.

Having someone who was able to meet the bus each afternoon. Regular services on given days of the week.

To be able to return to work I would need the hours before and after work covered, in-home respite 7.30 am to 8.30 am and from 3 pm to 4 pm.

He gets really tired so in-home respite would be better.

6.6.2 Transport

The inclusion of transport to and from existing services as a component of any new arrangement is regarded as essential by all study respondents:

You battle to try and find services and then transport to services is a battle.

As we live 22 kms from a regional city, with no public transport, a considerable amount of time and cost goes into transportation in relation to getting to a disability service and providing access to entertainment. Two reliable cars are required.

Transport needs to be attached to all services and programs. There is no point getting Dan into a program if he cannot get to or from the program.

One participant explained why she is not currently participating in the paid workforce:

There are inadequate support services. There is no disability bus to get my son to his services. I have to drive him everywhere as it is not safe for him to use public transport.

The Companion and Taxi Cards are designed to facilitate community participation for people with a disability. All but one of the participants is caring for an adult who was eligible for a taxi card, although families' experiences of the taxi directorate were mixed and none use taxis regularly. Fran summed up the situation:

Taxis are good for emergencies, but far too expensive for day-to-day use. We have had some problems with the booking system.

Taxis can pose a particular problem for vulnerable people with an intellectual disability. Several carers reported that they do not put their adult daughters in taxis:

It had been quite good, but lately she hasn't wanted to use the taxi because a driver asked her out on a date.

Government funded outside-centre-hours activity programs for adolescents and adults with an intellectual disability are necessary to support carer workplace participation. These programs are needed to ensure that carers of people with a life long disability have choice in their lives and options for participation in employment which are equitable with support and services currently provided to families with younger children with disabilities.

Recurrent funding for outside-centre-hours care and vacation programs for adults with an intellectual disability

Recommendation 6

That the Commonwealth and State Governments work collaboratively to ensure the availability of recurrent funding to develop outside-centre-hours programs for adolescents and adults with an intellectual disability including:

- Activity and community participation programs which can be developed from existing day program venues from 8 am – 9 am and 3 pm – 6 pm daily, and during centre vacation periods; and
- Collaboration and partnerships between parents and service providers in the planning and development of programs with shared transport arrangements.

Framework for action

6.3 Table 4. A framework for action

Action	Responsibility & leadership	In collaboration with
<p>Recurrent funding for outside-centre-hours care and vacation care for adolescents and adults with intellectual disability.</p> <p>Alter HACC guidelines to explicitly support carers' workforce participation.</p> <p>Disability services and respite providers to adopt a family-centred approach.</p> <p>The funding of regular, predictable and ongoing respite for caring families.</p>	State Governments	<p>Disability and carer peak bodies and advocacy organisations;</p> <p>Disability service providers;</p> <p>HACC service providers;</p> <p>Caring families; and</p> <p>Transport providers.</p>
<p>Provide DEEWR PPP training places for people on the Carer Payment.</p> <p>Review the 25-hour rule for Carer Payment recipients and eligibility for the Health Care Card.</p> <p>Examine the impacts of EMTR's on people in receipt of the Carer Payment.</p> <p>Leadership and collaboration with employers and the private sector to strengthen legislation that supports flexible workplace practices.</p>	Commonwealth Government	<p>Employers to work with the Commonwealth Government to meet legislative requirements;</p> <p>Carer peak bodies and advocacy organisations, to disseminate information about legislative changes and training opportunities; and</p> <p>Training for service providers.</p>
<p>Work towards workplace modernisation to ensure that workplace policies and practices are consistent with legislative change and ensure more workers have greater access to flexible conditions.</p> <p>Greater promotion of best practice in the provision of flexible work provisions – through programs such as the EOWA, Employer of Choice Awards.</p>	Employers	<p>Employer representatives;</p> <p>Commonwealth government;</p> <p>Statutory authorities;</p> <p>Employee representatives; and</p> <p>Carer peak bodies and advocacy organisations.</p>

Table 4. A framework for action.

7 Conclusion

This study has demonstrated a need for a three-fold focus to remove the current barriers to carer labour force participation. Greater collaboration between the Commonwealth, State and Territory governments and employers will involve a key focus on:

1. improving and expanding services and supports for people with disability to support the labour force participation of their families;
2. education and training for carers to give them the necessary skills to re-engage or stay competitive in the labour market; and
3. recognition of the caring role within the workplace; strengthening legislation and the provision of flexible work arrangements.

Caring families need a service system and income support provisions which enable them to choose their level of labour force participation. The current risks associated with life course transitions of carers from work to care, care to training, and care to work need to be reduced. The provision of outside-centre-hours and vacation care would significantly reduce these risks. The current service system needs to expand to ensure that the need for care of children, adolescents and adults with intellectual disability outside current centre hours is met. Changes to the current income support provisions for carers which support work and study would further reduce the risks that carers face in transitioning from one life stage to another.

The current services system assumes a primary carer will be at home between the hours of 3 pm and 9 am during the week. They will coordinate services, provide transport, emotional, social, personal care and supervise the needs of their adult sons and/or daughters. The service system also assumes that carers will undertake limited paid work outside the home between the hours of 10 am and 2 pm and be available during vacation periods for six or seven weeks of the year. Many mothers who are primary carers are obliged to stay at home.

For sole parent carers, the provision of services and supports that enable greater labour force participation is vital. For partnered parent carers, policies that promote a 'shared-care' approach within families would enable an equitable distribution of caring responsibilities and greater workforce participation for *both* parents. One respondent put it this way:

Better service provision would mean that paid employment would be easier for carers to access. Also those carers who cannot access work or, who find working arrangements too challenging given their full-time caring role, would be able to have a healthier lifestyle.

This study has highlighted that primary carers are at particular risk of social and economic exclusion. A coordinated effort by caring families, advocacy organisations and service providers is required to ensure a whole of government response to reducing the barriers faced by primary carers in making choices around their level of participation in the paid workforce. The current lack of entitlement and access to substitute outside-of-centre hours care results in an inequitable and unsustainable situation for primary carers who are central to the current delivery of community care for adolescents and adults with intellectual disability.

Long-term family carers and the people to whom they provide care are among the most disadvantaged groups in Victoria. This is largely due to their precarious relationship to, and long absences from, the labour force. Many family carers have neither the time nor the resources to invest in continuing their education and training. They are concentrated in low-skilled jobs, and employed under tenuous employment arrangements. They have little prospect of fulfilling their potential and few opportunities to accrue superannuation savings.

The Intergenerational Report 2010 identified Australia's looming need for labour. Leadership by the Commonwealth Government is needed. It must invest in the training of family carers to provide them with the skills required in a changing labour market. It should as a priority commit to the targeting of training places for Carer Payment recipients, as part of the Productivity Places Program administered by DEEWR.

The Commonwealth Government must work collaboratively with state and territory governments, employers and their representative bodies to ensure all carers have the right to request flexible work. The National Employment Standards must be expanded and a stronger compliance regime with grievance mechanisms to redress unfair refusal must be introduced.

Action by government is needed to empower the most vulnerable and disadvantaged members of our society. Removal of the structural impediments to carer workforce participation is needed. The provision of improved services and supports will ensure many carers can make choices about the work arrangements that best suit their individual and family needs.

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