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**The 'dignity of work': inclusion through participation
for people with a mental illness and their carers**

Submission to the House of Representatives Standing Committee
on Education and Employment Inquiry into Mental Health and
Workforce Participation

Jointly submitted by Carers Australia and Carers NSW

April 2011

About Carers Australia

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians. They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

Carer Australia's vision is that caring is accepted as a shared community responsibility and our mission is to lead change and action with and for carers.

Carers Australia works in partnership with its members, the eight state and territory Carers Associations.

About Carers NSW

Carers NSW is the peak organisation for carers in New South Wales. It is a member of Carers Australia and works as part of the national Network of Carers Associations. Carers NSW has an exclusive focus on supporting and advocating for all carers in New South Wales.

The core work of Carers NSW is to:

- be the voice for carers in New South Wales
- undertake research, policy development and advocacy
- provide carer services and programs
- provide education and training for carers and services providers
- build capacity in the sector.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in New South Wales are recognised, valued and supported by their communities and by governments.

The goal of all of the work Carers NSW undertakes is for carers in New South Wales to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural or linguistic background.

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About carers

A carer is any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful.

In relation to this submission and the Inquiry it is important that the Committee understands that there can be many different types of care relationships for people with a mental illness, and that care is provided in different contexts, and different environments. A report prepared for the Australian Government Department of Health and Ageing, *Identifying the Carer Project*, highlights the diversity of relationships between carers and people with mental illness, including:

- Indigenous communities
- culturally diverse communities
- complex family situations
- same sex communities
- rural and remote communities.¹

These different communities will have varying support requirements for the person with the mental illness and the individual or individuals caring for them.

Key statistics about caring

According to statistics on carers from the Australian Bureau of Statistics 2003 *Survey of Disability, Ageing and Carers* (SDAC):*

- 40 per cent of primary carers cared for a partner, 29 per cent for a child, 32 per cent for other (e.g. sibling, parent)
- women aged 45-54 years were the largest single group of carers
- 45 per cent of primary carers provided 40 hours or more care per week on average
- 78 per cent of primary carers lived with the person they supported
- 75 per cent of carers were of workforce age although 45 per cent were not in the workforce
- 55 per cent of primary carers relied on a government allowance or pension as their principal source of income.

* This data is drawn from the 2003 Survey of Disability, Ageing and Carers. The full summary of the ABS 2009 Survey of Disability, Ageing and Carers is still to be released.

Introduction

Carers Australia and Carers NSW are pleased to make this joint submission to the Inquiry into mental health and workforce participation being conducted by the House of Representatives Standing Committee on Education and Employment (the Committee).

Workforce participation is of fundamental importance to people with a mental illness and to their families and carers. Employment, together with stable housing and good health services, is a key factor in keeping people with a mental illness well.² Education and employment provide people with a mental illness with opportunities to regain a routine, improve quality of life, and expand their social and community connections beyond the mental health system and their carer.³ These opportunities are of huge benefit to the individual in question, and to those who care for and support them. Improving workforce participation for people with a mental illness has the potential to make significant improvements to the wellbeing of people with a mental illness, and to the wellbeing of the families and carers who provide the majority of care and support.

It is important that the Committee recognise and understand the role of carers in providing care and support to people with a mental illness, and the impacts that caring has upon carers. We believe that carers must be included and recognised in the report and recommendations of the Inquiry, including their role in supporting people with a mental illness to participate in the workforce. It is disappointing that there is no explicit reference to carers in the Terms of Reference of the Inquiry, particularly given the recent introduction of the *Carer Recognition Act 2010*, and the development of the National Carer Strategy. The *Carer Recognition Act 2010* contains a *Statement for Australia's Carers* which outlines ten principles which should inform the both the conduct of this Inquiry and its findings.

It is our hope that this Inquiry will draw more attention to the workforce participation of people with a mental illness, and act as a catalyst for meaningful change to the extent to which people with a mental illness and their families and carers are able to participate in the workforce and in the community.

About this submission

As Carers Australia and Carers NSW are both peak bodies for carers, this submission will largely focus on the Terms of Reference as they relate to carers. It has been informed by consultations held with carers of people with a mental illness who are members of the Carers NSW Carer Representation Program, and other research on carers.

The submission will focus on the impacts of caring for a person with a mental illness, particularly upon the carers own participation in the workforce, and on the role of the carer in improving the participation of people with a mental illness in education and employment. It will share responses provided by carers to the Terms of Reference of the Inquiry. Finally, the submission will address the need to include carers in the delivery of employment services to people with a mental illness.

This submission will not specifically address the needs of people with a mental illness and their carers from different population groups or communities. This does not preclude the need for the Inquiry to consider the special needs of these groups, particularly those defined above in 'About carers'.

1. The experience and impacts of caring for a person with a mental illness

Carers are central to the care and support of people with a mental illness, and are the major providers of care in the community. In the wake of de-institutionalisation and the failure to adequately resource and develop alternative care services in the community, carers have had to step in to care for people with a mental illness, often in isolation. In 1993, the landmark 'Burdekin report' identified that carers carry an 'enormous and unreasonable burden of care' and that caring has adverse effects on their physical, emotional and mental health and imposes heavy financial strains.⁴

A snapshot of statistics from the *2010 Mental Health Carers Survey* provides some insight into the experience of caring for a person with a mental illness. The survey found that:

- 31 per cent of respondents had been caring for between 11 and 20 years
- the median length of time spent caring was 10 years, the maximum was 54 years
- 77 per cent of respondents were responsible for organising the majority of care for the person they care for
- one fifth of respondents cared for more than one person with a mental illness.⁵

Caring for a person with a mental illness is often much more than a full time job. Carers of people with a mental illness were found to spend an average of 104 hours caring per week, according to a report by Carers Australia and the Mental Health Council of Australia.⁶

It is important that the Committee understands the kinds of support provided by carers and how their support links to the potential workforce participation of the person with a mental illness. The final report of the *Identifying the Carer Project* provides a useful summary of the type of care and support that carers provide. According to the report this includes:

- providing emotional support, sometimes for protracted periods each day
- encouraging the use of medication, checking compliance and observing for side effects
- assistance with personal affairs, such as bill paying and Medicare claims
- reminding the care recipient of appointments and ensuring they get to them
- helping with understanding of medical decisions about treatment
- checking to see there is food in the fridge, and sometimes making meals
- helping with household chores such as cleaning, shopping, lawn care, etc
- making regular phone calls to the consumer to "check in" on them
- assisting with the maintenance of social activities.⁷

These types of support will in many cases be critical to a person with a mental illness successfully participating in education or employment.

The report noted the additional assistance provided during acute episodes. This includes:

- management of unpredictable and sometimes paranoid and/or aggressive behaviours

- notifying treating staff and negotiating appointments in situations where the consumer has an ongoing relationship with a private psychiatrist or community team
- transportation to services which in some cases may require negotiations with the police
- visiting the consumer if they are hospitalised
- assistance to other family members to enable them to understand what is happening.⁸

The substantial and invaluable care and support provided by carers to people with a mental illness comes at a considerable cost to carers, particularly in terms of their own health and wellbeing. The remainder of this section will explore some of these costs.

1.1 Physical and mental health

It is well established that caring (regardless of the nature of the disability or condition experienced by the care recipient) has significant detrimental impacts on the physical and mental health of carers. Carers Australia described caring as a 'health hazard' in their report on the 1999 *National Survey of Carer Health and Wellbeing*.⁹ Over half of respondents to this survey had suffered a decline in physical health, a third had experienced a physical injury, and over half believed they had worse overall mental and emotional health.

These findings have been supported by a significant body of evidence. For example, research by the Australian Institute of Family Studies published in 2008 found that carers experience high rates of mental health problems, poor physical health and relationship breakdown, among other impacts.¹⁰

The findings of the 2007 *Australian Unity Wellbeing Index Survey* are also telling. This survey found carers to have the lowest collective wellbeing of any known population group, with the wellbeing of carers who live with the care recipient being the lowest ever recorded for a large group of people. The survey found that carers have an average stress rating that is classified as moderate depression, are more likely to experience chronic pain than is normal and their wellbeing is more vulnerable to pain.¹¹

Research specifically focused on the carers of people with a mental illness supports these findings. Nearly half of respondents to the *2010 Mental Health Carers Survey* reported their health was 'slightly worse' and a further 25.1 per cent reported their health was 'much worse' as a result of being a mental health carer.¹² A number of respondents reported taking various medications as part of their coping strategy. Almost a third took sleeping pills, around a third took anxiety medication and 37.1 per cent took antidepressants.

Carers of people with a mental illness often neglect their own health care, exacerbating the negative impacts caring has on their health. For many carers of people with a mental illness, looking after the health of those they care for was their priority. Time and financial factors prevented them from looking after their own health as well as the care recipient's.¹³

1.2 Direct financial costs

The financial impacts of caring for a person with a mental illness can be significant and life long. Direct financial costs are often substantial and may include:

- medication
- medical appointments
- transportation
- costs relating to the behaviour of the care recipient when they are unwell, such as damage to property, fines and financial commitments
- everyday living costs such as for accommodation, utilities and groceries.¹⁴

Some indication of the extent of these costs is given in the *2010 Mental Health Carers Survey*. The median fortnightly amount spent by respondents on the care recipient was \$100, while almost one third of respondents spent \$200. For those carers who are financially responsible for the accommodation costs of the care recipient, maintaining two households can be enormously challenging, particularly given the high cost of housing throughout Australia,¹⁵ and the low income levels associated with caring (see section 1.3).

Carers of people with a mental illness report drawing on their savings and superannuation in order to meet the direct financial costs of their caring role. The *Carers NSW 2010 Carer Survey* found that 65 per cent of carers of people with a mental illness had had to borrow money as a result of their caring role and almost half had trouble paying for basic items.¹⁶

That carers were more likely to need to draw upon savings or other assets than non carers was also reinforced in research conducted by the Australian Institute of Family Studies in 2009 for Carers Australia.¹⁷

1.3 Indirect financial costs

At the time I became a carer for my daughter I was working. Because of the commitment and difficulty of the illness I found it impossible to work and cope with carer responsibilities. I took all my leave and then retired to focus on caring.

I am unemployed. I worked in a corporate environment but then my son became ill and the stress associated with that and work changed how I viewed my life forever. I now only want mundane jobs where there is little stress associated with the role. So my life had changed dramatically as well.

Responses cited in the *2010 Mental Health Carers Survey*

The indirect costs of caring, particularly the long term costs of leaving or reducing employment, or accepting lower-paid employment, are highly significant and can have life-long consequences. There is consistent evidence that carers have lower rates of participation in the labour force, lower rates of employment and that those who are employed work fewer hours. Data from the 2003 SDAC indicates that the labour market participation of primary carers was less than half that of the general population. According to this survey, just over half of unemployed primary carers had left work specifically to start or increase care (51 per cent). The survey found that 44

per cent of primary carers were living in low income households and that 57 per cent had a government pension or allowance as their main source of income.¹⁸

The impact of caring on income and savings capacity are compounded by the direct financial costs discussed in the preceding section, meaning that the financial stress experienced by carers is greater than what may be indicated by looking at income levels alone. This is supported by the 2008 study *Negotiating caring and employment*, which found that carers in the study had a rate of financial stress that was twice that experienced by the general population at the same income level.¹⁹

There is limited literature available on the experience of mental health carers, but given what is known about the length and intensity of their caring, it is likely that they experience significant impacts on their workforce participation, and therefore their long-term financial wellbeing. There is also evidence to suggest that the financial situation of carers of people with a mental illness worsens when the people they care for experience a relapse.²⁰ Many carers participating in the *Carers Engagement Project* reported that they would like to be employed in paid work, or in full-time rather than part-time work, but that this would be “impossible” to achieve in conjunction with their caring role.²¹

1.4 Stigma and discrimination

Carers of people with a mental illness experience extremely negative effects of stigma and discrimination arising from their caring role.²² Caring for a person with a mental illness is highly stigmatised, and both carer and care recipient are subject to discrimination. Ninety-five per cent of respondents to the *2010 Mental Health Carers Survey* stated that stigma and discrimination were widespread or existed to some extent.²³

As a result of the stigma and discrimination associated with their caring role, carers experience significant difficulties with their own families, in employment, in education (particularly for young carers) and in treatment settings.

Stigma contributes to the social isolation of carers, who often feel disengaged and disconnected from their communities. Fifty-eight per cent of respondents to the *2010 Mental Health Carers Survey* ‘always’ or ‘often’ felt alone.

2. The impacts on carers of the low employment participation of people with a mental illness

In addition to the day-to-day care and support described in the section above, carers also provide much support specifically to help people with a mental illness participate in education and employment. The provision of this support comes at a cost for the carer, particularly as it is the source of much frustration and can impact upon the carer’s own workforce participation.

2.1 Involvement in supporting the person to gain employment

Carers often provide significant support to people with a mental illness in their efforts to obtain and maintain employment or participate in education. Carers often play a very significant role in providing emotional support, encouragement, guidance and motivation. They also provide very practical and tangible supports including actively seeking opportunities on the person’s behalf, providing or organising transport, assisting with paperwork, and providing assistance and advice regarding a wide

range of issues. Some carers also assist the person they care for with the comprehension and retention of information and remind them of commitments and appointments. Many carers provide advice and assistance with a range of life and employment skills such as communication, appropriate dress, punctuality, personal hygiene, and so on.

A carer involved in the consultation conducted by Carers NSW for this submission described herself as 'terribly involved' in her son's search for employment:

... It is very prominent in our lives at the moment, I am very involved in his job search. Driving him around places, helping him write a resume, making phone calls, organising a PHAM's worker to come. I'm spending every Monday teaching him to make phone calls, and how to approach people... being his tutor and teacher all the time is a strain.

Another carer in the consultation described the advocacy role she has taken on for her son to help him gain access to appropriate employment assistance, and to gain positions relevant to his skills and qualifications. This has involved active engagement with potential employers, disability employment services and other contacts.

2.2 Frustration

It feels like we take one step forward and ten steps back.

Carer comment in Carers NSW carer consultation

Carers experience a great deal of frustration in their attempts to help the person they care for participate in education and employment. The barriers and setbacks experienced by people with a mental illness are a cause of frustration to themselves and to the people who support them. Carers describe being very frustrated and upset by the great difficulty people with a mental illness have securing and maintaining employment, particularly in light of the importance that achieving these goals has for their recovery and wellbeing.

It is particularly frustrating for carers to know that the recovery of the person they care for, which has often been hard fought for, is jeopardised by the barriers they face in gaining employment. Often despite the person they care for being well and able to work, they are unable to get work and as a result remain at home with nothing to do. As one carer in a consultation for this submission stated:

It is very frustrating for the carer, when the person with a mental illness is well but has nothing to do, just sitting at home.

Another carer expressed the great frustration she experiences as her efforts to assist her daughter are frustrated.

Carers are left sitting frustrated, distressed, getting angrier or just feeling defeated with the stops and starts.

2.3 Carers' own participation is contingent on the participation of the person they care for

The Australian Government recognises that an important aspect of social inclusion is having the opportunity to work... all Australians, including those with disability, should have the opportunity to find and keep a job.

From the Australian Government *Social Inclusion Agenda* ²⁴

The Australian Government recognises that an important aspect of social inclusion is having the opportunity to work, and has included people with mental illness and their carers as a priority group in its social inclusion agenda. This recognises that carers, like people with a mental illness and indeed all other Australians, should have the opportunity to work. The Australian Government has developed mental health and disability frameworks to address this issue. However, carers continue to experience significant barriers to their own workforce participation, as discussed above (see section 1.3).

Often the carer's participation in education or employment hinges directly on the health of the person they care for and their participation in employment or education. One carer in the consultation held for this submission described being unable to move forward until her son gained employment.

Getting my son into work is such an integral part of his recovery, it is the most important goal... I am holding my breath, I can't move forward until that happens... This is the most important goal and to reach it is crucial. I can't move forward to do my own thing until this happens.

Carers describe how their own participation in employment is directly impacted upon by the health of the person they care for, and by their engagement in either education or employment. When the person they care for is unwell it can be very difficult and stressful for carers to go to work. Unless there are other supports available, which is seldom the case, carers are often forced to try and monitor and support the person with a mental illness from their workplace. This may mean making and receiving multiple phone calls, returning home to check on them during the day, or trying to deal with challenging behaviours and incidents while working.

Even if the person they care for is well, it can be difficult for a carer to seek or maintain a job if the person cared for is at home every day. At home, alone, that person may become isolated, without much to do and perhaps at risk of becoming unwell. In recovery the person they care for may require significant support, and those who are looking for employment often require significant support from the carer as detailed above (section 2.1). It is difficult for carers to keep their own work commitments if, for example, the person they care for relies on them for transport to get to appointments with disability employment services and potential employers, in addition to the other support and encouragement that may be required.

The *Identifying the Carer* report also stressed the difficulty that employed carers of people with a mental illness experience.²⁵ The report noted that caring responsibilities exacted a price and argued that support for carers could reduce the strains they experienced in their daily working lives.²⁶

Carers can also be excluded from participating in employment assistance schemes and other support programs by their caring responsibilities. For example, many carers of people with a mental illness would be unable to participate in the New

Enterprise Incentive Scheme (NEIS). NEIS is a self-employment program, funded by the Department of Education, Employment and Workplace Relations, for unemployed people who wish to start their own business. This could be of great potential for many carers who would benefit from the flexibility of being self-employed, and running, for example, a home-based business. However, the design of the scheme is exclusive of carers due to the requirements for participants to complete full-time training, and to operate the business on a full-time basis.²⁷ Carers WA has recently provided assistance to a carer who was unable to participate in the NEIS due to their role as a carer of a person with a mental illness.

3. Carer insight into the Terms of Reference of the Inquiry

Carers have unique expertise and insight into the experiences and needs of people with a mental illness. Their perspective should be valued and included both at an individual level and at decision making and policy setting levels. We urge the Committee to ensure that this Inquiry recognises and values carer expertise, and the individual responses and experiences included here.

Carers NSW invited carers of people with a mental illness to contribute to this submission by providing written comments or by participating in a consultation held by teleconference. Three carers participated in the consultation. The results of these conversations, and previous focus groups held for the *Carers NSW 2010 Carer Survey* are the basis for this section of the submission, which gives voice to the insight of carers into the Terms of Reference of this Inquiry.

3.1 People with a mental illness 'aren't given a chance'

Carers testified to the significant barriers experienced by people with a mental illness in their efforts to participate in education and employment. The experiences of the carers in the consultation were that it was very difficult, if not impossible, for the people they care for to even 'get a foot in the door'.

One carer related the experiences of her daughter, who has studied on and off for several years. The final requirement of her course is to complete a work experience placement, but she has been unable to do this. Once employers meet her and see the physical signs of her self-harming behaviour they are unwilling to provide a placement. She cannot qualify or gain employment in the field without completing the work experience, despite having met all the other course requirements.

Another carer described her son's situation, who has been studying and looking for work for three years. Despite having qualifications and skills, he gets no replies to his applications for employment. In the carer's opinion, his resume is treated as 'a piece of paper that gets thrown in the bin'. His transition from education to employment upon leaving school was interrupted by his illness, and several years down the track his age and lack of experience mean he is getting no opportunities, and therefore is unable to gain the experience which seems to be a prerequisite for any employment.

Gaps in employment histories due to periods of ill health, the disclosure of mental illness to potential employers and physical signs or manifestations of the mental illness (or medication) are significant barriers regardless of the skills, qualification and experience that an individual may possess.

3.2 Disability employment services

The carers participating in the consultation expressed frustration with the disability employment services accessed by the people they care for. Serious concerns were raised regarding the quality and appropriateness of some of these services. Carers commented that:

- people with a mental illness were being ‘palmed off’ from one service provider to another
- initial promises of work experience and other assistance were broken
- resumes and applications written with the assistance of employment consultants were sometimes of a very low quality
- the qualifications and skills of the person with a mental illness were disregarded
- individual support plans, including limitations nominated by the person with a mental illness, were ignored
- there was a lack of consistency and continuity in the service providers and staff providing assistance, due to the results of competitive tendering processes and high staff turn-over within organisations.

Carers also raised concerns regarding the capacity of some staff and organisations to work with people with a mental illness. The carers in this consultation believed that few employment consultants had the knowledge and skills necessary to work with people with a mental illness, and to understand and respond to their needs and experiences.

Carers related that staff often did not understand the effects that mental illness can have on some people’s communication, comprehension, and capacity to plan. There was little understanding of the need of some people with a mental illness for encouragement, assistance to understand information being provided and for reminders afterwards of what has been discussed and agreed. Some individuals may benefit from their carer being present to meet (or explain) these needs, and staff need to modify their own communication and work practices to ensure that they respond adequately to the needs of each individual they assist.

Concerns were also expressed relating to the appropriateness and accessibility of opportunities being offered to people with a mental illness by disability employment services. Examples include a work experience program that was inaccessible by public transport, ignoring the fact that many people with a mental illness do not have access to private transport. Another program offered started at 8:30 am each day, despite the great difficulty many people with a mental illness experience in waking and starting work early.

The concern of carers that the people they care for will not benefit from being offered inappropriate or poor quality opportunities is supported by research published by the Australian National University’s Centre for Mental Health Research. According to this study the relationship between employment and health is complex, and employment will not necessarily lead to mental health improvements. Good quality work is required for people to gain and maintain better wellbeing.²⁸

3.3 Transport

Transport was raised as a significant issue for many people with a mental illness. Outside of metropolitan centres there is often a paucity of public transport which

makes it difficult for people with a mental illness, who may not have access to private transport, and may depend upon family and friends to drive them, to attend employment services, job interviews or employment.

Even in metropolitan centres, where more public transport options are generally available, transport can prove a barrier. It may be that the journey by public transport to the employment service is long, that there is limited frequency or that connections do not synchronise adding to travel time. This is particularly complicated when early morning starts are required.

For some people with a mental illness, managing a trip on public transport, particularly one that involves multiple connections, can be challenging and may be a serious disincentive to participation in job search, education or employment.

4. Solutions for consideration by the Committee

The following recommendations were made in the consultation held with carers of people with a mental illness, and are presented for consideration by the Committee.

4.1 Education and training

Staff of disability employment services, and any other service which supports people with a mental illness to participate in education or employment, require education and training to ensure that they are able to work effectively with people with a mental illness.

Employment consultants in particular need a better understanding of the impacts of mental illness and common medications in order for them to better understand the needs of their clients in the job search process and in employment.

Education and training should also be provided to ensure that employment consultants have the skills to communicate with and support people with a mental illness appropriately.

Carer awareness training should be provided to all disability employment services to ensure that staff respect and understand the care relationship, include and work with the carer appropriately, and benefit from the insight of the carer and their support of the job search process. Carers must be involved in employment services, and be kept informed appropriately so that they are able to understand and support the actions being implemented by the employment consultant and the person they care for.

4.2 Greater collaboration between services

Better collaboration between employment service providers, mental health services and other agencies providing support to the person with a mental illness (with the permission of the client) will ensure that all parties are working towards the same goals, and supporting the recovery of the client in different areas of their lives.

If services worked together, where appropriate, the person with a mental illness would be better supported, and the agencies or service providers supporting them would be better informed and more able to provide a tailored approach to care and support. Currently there is very little integration or collaboration between different

health services, or between health services and other community services such as housing or employment services.²⁹

Collaboration may provide the person with a mental illness with a stronger sense of identity and personhood within the service system, and help them to feel that they matter, and that their progress and recovery is valued by those supporting them.

4.3 Long-term incentives for employers

A suggestion strongly supported in the consultation was for long-term incentives to employers to support the employment of people with a mental illness. Existing incentives are often short-term. After a short period in employment the employer may have no incentive to continue employing the person, particularly if they continue to require support in adjusting to the workplace or to their role, they are experiencing ill-health or if the employer has any concerns about their performance or capabilities.

Some form of incentive is required to motivate employers to make an effort to support the person with a mental illness beyond the initial 13 weeks that incentives are usually available for. Incentives are needed to ensure that employment is not only gained but also maintained. Often some investment of time and energy is required from employers or supervisors to sustain the employment of people with a mental illness, particularly in the early stages of their employment, and to address any challenges or issues that arise in this time.

Long-term incentives may help to encourage employers to give people with a mental illness the time and opportunities that they need to prove their value as employees, instead of providing an incentive to take someone on in the short term, and then terminate employment after the first 13 weeks.

4.4 Quality, long-term job maintenance services to support employees and employers

Incentives, particularly financial incentives, should not be the only investment in helping people with a mental illness to maintain employment. As well as longer term incentives, quality long-term job maintenance services are needed to help people with a mental illness stay in employment.

Although disability employment services currently provide job maintenance services, the carers in this consultation envisaged job maintenance services that are available in the longer term, that are of greater intensity (when required), and delivered by people with the appropriate skills and qualifications. Such services could be accessed if the person experiences ill health, or their circumstances change. For example, one carer raised the need for staff with mediation skills to be able to liaise between the employer and employee to support the relationship and address any issues that have arisen for either party.

The value of mentoring was also raised, and the provision of paid mentors who could visit and support people with a mental illness, and assist them to deal with any challenges or concerns they experience in the workplace, was recommended. This is one way to support both the person with a mental illness and their employer. The mentor could provide support in person and by telephone and internet.

The provision of this type of job maintenance service would also help to meet the needs of employers and colleagues. Often it is difficult for employers and colleagues to deal with the changes that can occur in the person with a mental illness's

behaviour, appearance and demeanour when they are unwell. Often people feel uncomfortable in this situation, and are unsure of how to respond or what action, if any, they should take. Even employers with the best of intentions and a desire to continue employing the person with a mental illness may struggle to support the person in this situation.

Access to job maintenance services which include a liaison person and mentor who could provide support and advice to employer and employee, improve communication, and sustain the relationship, could significantly improve the ability of people with a mental illness to maintain employment, even when they become unwell.

Another suggestion made was for the provision of subsidies for the replacement staff that are required in the event that the person with a mental illness is unwell and needs time off work. Too often a period of ill-health leads to termination for people with a mental illness. Provisions for a temporary employee to cover the role of the person with a mental illness whilst they recover is an idea with complex ramifications, but one that is not without merit.

4.5 Education and training for employers and colleagues

Education and training to enhance the ability of Australian workplaces to support people with a mental illness would also be of great value. Workplaces would be more inclusive and supportive of people with a mental illness if employees at all levels had more knowledge about mental health and about supporting a person with a mental illness. Awareness and knowledge of mental illness in the workplace could be improved through education and training delivered face-to-face, online, or through resources provided online or in print.

An example of a recent initiative that could be applied to mental health is *A Guide to Employer Engagement - From the Employers Voice*. This guide has been funded by the Australian Government's Innovation Fund to help employers "make the most of the talents of their employees with disability." It includes employment engagement guidelines and advice for employers seeking to recruit people with a disability. Face-to-face and interactive online seminar briefing sessions, including employment-based case studies, will be available to providers of disability employment services as part of this initiative.³⁰ A similar initiative relating specifically to mental health could be considered.

4.6 Champions for the employment of people with a mental illness

Champions for the employment of people with a mental illness may help to reduce the stigma associated with mental illness in the workplace and improve awareness of this issue. Champions would also provide leadership and encourage employers to increase their employment of people with a mental illness and to participate in initiatives and programs to support the employment of people with a mental illness.

Major employers should be encouraged to publicly support and address the workforce participation of people with a mental illness. Many major employers already have established commitments and strategies relating to corporate social responsibility, often including the employment of people with a disability. For example, WorkFocus Australia and Woolworths Ltd have recently announced a new program to boost employment of people with a disability and create a model for other major employers. The program will analyse roles in Woolworths to identify

opportunities and workplace adjustments that can be made for people with a disability, and to identify and remove barriers to people with a disability.³¹

Similar programs targeted specifically at people with a mental illness and the particular issues and barriers that they experience could be facilitated by the Australian Government to provide leadership to employers in this regard, and improve the participation of people with a mental illness.

Consideration could also be given to improving the proportion of employees with a mental illness employed by government departments, agencies and government-funded services, especially those in the disability and mental health sectors.

5. Improving carer recognition and inclusion in employment services

Carers should be recognised, included and supported in the delivery of employment assistance to people with a mental illness. The *Statement for Australia's Carers* should inform the delivery of disability employment services, including that:

6. The relationship between carers and the persons for whom they care should be recognised and respected.
7. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
8. Carers should be treated with dignity and respect.

From the *Statement for Australia's Carers*

The experiences of the carers involved in the consultation for this submission suggest that these principles are rarely upheld by disability employment services. On the contrary, carers are generally excluded by employment services. This is an issue that needs to be addressed by the Committee in any analysis or recommendations to be made relating to the delivery of employment assistance to people with a mental illness.

The benefits of including carers and their expertise to the carer, the person they support, and to service providers are considerable. Carers have a unique insight into the needs and experiences of the person they care for. They are often the main source of support to people with a mental illness, and should be included and informed to ensure that they are able to effectively support the person's participation in employment services, their individual support plan, and any goals or action plans they have developed. This may be support in the form of encouragement and emotional support, or it may be the provision of practical support such as transport to job interviews or training programs.

Carers often have a pivotal role in organising services and gaining access to the services needed by the person they care for. Seventy-seven per cent of respondents to the *2010 Mental Health Carers Survey* indicated that they were responsible for organising the majority of care for the person they care for.³² It is illogical for carers to be systematically excluded from employment services when in so many cases they have such a significant role regardless of whether the employment service includes them or not. It is better for all concerned that the carer is included, and that

the person with a mental illness, the employment service, the carer and any other services providing support work together.

Carers can be included in the delivery of employment services without violating any rights of the person with a mental illness. Too often in the mental health sector, concerns (that are often uninformed or unfounded) regarding confidentiality result in the automatic exclusion of carers. It is important that carers are included in an appropriate, legal and ethical manner, with the permission and knowledge of the client, without infringing upon the rights of the carer, or overly increasing the care responsibilities they are already balancing with their own life and other responsibilities.

6. Other issues

There are other issues relating to the mental health sector more generally which should be considered by the Committee, due to their relevance to the participation of people with a mental illness in employment and education.

6.1 Need for improved mental health services

A crucial factor in the participation of people with a mental illness in education and employment is their health, and the quality of the health services that are available to them to promote recovery and prevent relapse.

As this Inquiry is focused on participation in employment and education it cannot and should not attempt to comprehensively address the quality and availability of mental health services. However, it would be remiss of the Committee not to support the need for significant reform and investment to ensure that accessible, high quality mental health services are available to all Australians.

The importance of facilitating access to mental health services to prevent relapse, instead of the current situation where many people do not receive assistance until they are acutely unwell, should be addressed by the Committee. This issue is particularly pertinent to participation in education and employment of both the person with a mental illness and their carer. In the absence of adequate mental health services, it is often the carer who provides care and support to the person with a mental illness when they become unwell, and who must take on the often difficult and time consuming task of gaining access to mental health services on the person's behalf.

6.2 Importance of research, development and evaluation

The provision of support to people with a mental illness and their carers, particularly relating to participation in education and employment, should be informed and underpinned by research, development and evaluation, including trials of new models of support and assistance.

Australian mental health research is highly regarded internationally, but is not well utilised within Australia to support service innovation or reform.³³ The 'blueprint' recently released by the Mental Health Reform Group may provide the Committee with some insight into the changes needed to mental health research in Australia. Research was nominated as one of the eight priority areas in the 'blueprint'.³⁴

Mental health research is currently receiving some attention at a national level. The Australian Government National Health and Medical Research Council recently conducted a Mental Health Workshop attended by eighty key stakeholders, the significance of which was acknowledged by the Minister for Mental Health and Ageing, Mark Butler.³⁵

The need for research, development and evaluation should be the subject of consideration and recommendations by the Committee. This is a valuable opportunity to ensure that participation in employment and education by people with a mental illness is not disregarded in the future mental health research agenda.

Conclusion

Carers Australia and Carers NSW appreciate the opportunity to provide a submission to this Inquiry, which addresses an issue of the utmost importance to Australian society at large, and to the individuals who are so significantly affected by their exclusion from the workforce, whether it is because they have a mental illness, or because they care for somebody who does.

It is our hope that this Inquiry will be the catalyst for significant improvements in the workforce participation of people with a mental illness and their carers. We believe that the Committee must seize this opportunity to provide further momentum to the current push to transform mental health services in Australia. As expressed by the 2010 Australian of the Year, Professor Patrick McGorry:

We are at a tipping point for mental health... Not only can we no longer afford to do nothing, we now have the opportunity, capacity and momentum to deliver genuinely transformational change.³⁶

Carers Australia and Carers NSW look forward to the report and recommendations of the Inquiry, and to the improvements that they will lead to in the workforce participation of people with a mental illness and their carers.



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End notes

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