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**“Daily bread, income and living with mental illness”
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Submission by the ACT Mental Health Consumer Network to inform the NACMH’s advice to the Minister for Health and Ageing on the extent of income-related difficulties faced by people with mental illness and their families and how these difficulties might be remedied

This submission has been prepared by the ACT Mental Health Consumer Network (the Network) in response to an invitation from the National Advisory Council on Mental Health (NACMH) to tender a written submission on ‘*Daily bread, income and living with mental illness*’, for the purpose of informing the NACMH’s advice to the Minister for Health and Ageing on the extent of income-related difficulties faced by people with mental illness and their families, and how these difficulties might be remedied.

The ACT Mental Health Consumer Network is the peak systemic advocacy body for mental health consumers in the ACT. Run by consumers for consumers, our aim is to bring about a higher standard of care in the mental health sector through representation, lobbying and active involvement in new developments in the mental health sector.

This submission is based on Network members’ personal experiences of living with mental illness.

QUESTION 1: HOW ARE PEOPLE WITH MENTAL ILLNESS AND THEIR FAMILIES FARING ON A DAILY BASIS? WHAT INCOME RELATED DIFFICULTIES DO THEY FACE?

Members of the Network regularly point to the challenges associated with securing and maintaining employment while living with mental illness. A large number of consumers of mental health services rely on the Disability Support Pension (DSP) and are therefore forced to survive on incomes of around \$15,000 a year, amounting to less than \$300 per week. This creates significant difficulties for consumers in juggling essential items such as paying rent, utilities, groceries and medical treatment whilst also trying to seek employment with limited resources at their disposal.

Key income-related difficulties experienced by mental health consumers in the ACT include:

Costs of seeking and maintaining paid employment

Many consumers express their intention to be involved in some sort of paid employment to earn additional income. However most are afraid of losing their Commonwealth income support and concession rental rebates. There are also hidden costs associated with seeking and maintaining employment such as transport, clothing, and childcare which can make the 'additional income' less than beneficial.

Barriers to re-accessing Disability Support Pensions

Consumers are concerned that the DSP eligibility criteria and the application process are problematic, and several have often experienced difficulties in accessing the DSP if they have received it and then ceased sometime in the past. Although the barriers to re-accessing the DSP may be motivated by a desire to promote employment, the effect is the opposite; barriers to re-access make mental health consumers reluctant to give up their DSP for employment in fear of facing difficulties re-accessing the DSP if their employment is unsustainable and/or their health deteriorates.

Lack of flexibility for workers with mental illnesses

Paid employment often fails to provide flexible environments for people managing their life with mental illness. Taking sick leave tends to be perceived as meaning that the employee has a low work ethic. It is difficult for workers with mental illness to hold down casual or part-time work because employers are often less inclined to continue employing people who have difficulties in filling their shifts. Most employment opportunities require regularity and stability, leaving little room for flexibility in case of relapse of mental illness or side effects of medication. At present, the DSP fails to provide an income safety net for people living with mental illness when relapses take place.

They (employers) discourage absenteeism. If I took too many sick leave or too often, then I will lose my job. DSP is my fallback but it does not work like that (Consumer voice)

Lack of access to bulk billing

Access to a bulk billing General Practitioners (GPs) is very difficult in the ACT; a problem is exacerbated for mental health consumers because they often require significant medical support from GPs, psychiatrists, psychologists, dentist, counsellors and other specialist, especially at times when they are struggling to manage their mental illness or – as is common for mental health consumers – when they are experiencing co-morbidity with physical or chronic illnesses. Many consumers struggle to meet the cost of services that are not bulk billed.

Lack of affordability for holistic treatment

Many consumers wish to seek holistic treatments and natural therapies as an alternative or complement to standard medical approaches. Many of these treatments, such as meditation and fitness classes, are often not covered by Medicare or Health Care Cards. This limits the capacity of consumers, particularly those who are facing financial hardship, to look beyond standard medical approaches to improve their wellbeing.

Challenges to good nutrition

Consumers often experience difficulties in obtaining nutritious yet affordable food. Cooking daily can be an overwhelming task for mental health consumers and an impossible task for people who are in an acute state of mental illness. There is very little support for gaining skills to cook nutritious and healthy meals. It is also difficult to access services that provide assistance for grocery shopping and meal provision. In addition, the Meals on Wheels service does not offer value for money and food vans offer little to no choice.

Transport difficulties

Cars and taxis are simply unaffordable for large numbers of mental health consumers. Public transport is often unavailable or inadequate outside of inner-city areas, especially outside of working hours and over weekend, and is becoming increasingly expensive. In addition, public transport is often difficult to use because many areas lack of journey planner internet sites.

It is hard for me to get out at night time to go to a community meeting because it hard to get the transport. (Consumer Voice)

Housing difficulties

Many mental health consumers live in public housing which exposes them to a range of issues which compromise their personal comfort and safety, and can exacerbate their mental illnesses. One Network member commented, for example, that *“I have had many experiences where my herb plants were destroyed by them [public housing providers]. They thought it was grass and they chopped it down. For me, to be connected with the natures help my recovery.”* Consumers do not choose to live in public housing; they either cannot afford private housing, or would only be able to afford private housing in areas that are isolated and far from the services they need.

In addition, there is increasingly high need of low cost services that offer supports for consumers to live independently or in supported housing, such as cleaning and home organising services, which currently are not available. Similarly to cooking skills, organising and cleaning a house can be overwhelming tasks for mental health consumers and an impossible task for individuals who are in an acute state of mental illness.

QUESTION 2: HOW MIGHT THE INCOME-RELATED DIFFICULTIES OF PEOPLE WITH MENTAL ILLNESS AND THEIR FAMILIES BE ADDRESSED?

The experiences and needs of people living with mental illness are incredibly varied and sensible policies must be based on this fact. Income-related difficulties should be addressed from the starting point that people living with mental illness will benefit from the freedom to use government and community supports to choose services that meet their needs.

Personalised budgets

The Network advocates for personalised budgets as the most important and urgent priority for addressing income-related difficulties of people with mental illness. This would allow people to access the services that best target their needs and that do this at suitable times and places. This approach promotes prevention and early intervention and supports consumers to have greater control of their lives. It also leverages market forces to drive services to respond better to consumer needs.

The idea of personalised budgets is not fanciful; the British Government has already started to transform the way it delivers public services to adopt a personalised support package approach¹. This 'personalisation' approach acknowledges that people receiving support should be able to make choices about how they live their lives, with state-funded services more tailored to individual choices and preferences in all care settings. This means thinking about public services and social care in an entirely different way. Every person can decide how to plan their support, develop a support plan outlining how their needs and outcomes can be met or to opt to direct their own support and have a personal budget.

The Liverpool City Council² has introduced personal budgets to place people at the centre of their service planning. It provides a personal budget to eligible recipients which is determined according to the recipient's individual care needs, based on the fact that some people need more support while others need less. The Council delivers its services based on the Seven Principles of Personalisation (see Appendix 1) which support the rights of the recipients and are consistent with a recovery approach for people living with mental illness.

¹ In 2007 Department of Health, United Kingdom, has launched a ministerial concordat on 'Putting people first: a shared vision and commitment to the transformation of adult social care' to promote a holistic approach and greater choice and control over the shape of support in all care settings. More detail visit:
<http://collections.europarchive.org/tna/20100509080731/http://dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm>

² Liverpool City Council (2010). *Information for people who use services, their families and carers*. Retrieved July 26 2010 from http://www.liverpool.gov.uk/Health_and_social_care/making_it_personal/information_for_people_who_use_services/index.asp

Being given access to a personal budget means mental health consumers can:

- purchase their own care and support if they choose to;
- purchase services that are tailored to suit their specific needs, preferences and circumstances;
- have greater control, choice and flexibility in their day-to-day lives; and
- be much more involved in helping government develop and shape services.

There are several ways that a personal budget can be spent and managed, but they are all based on the same key idea – consumers should get the care that they want, when they need it and in a way that suits them.

Disability insurance

The Network supports the idea of disability insurance, where people who decide to get off their DSP and enter paid employment can benefit from a safety net if they experience relapse and need to take some time off employment. Disability insurance should ensure that the costs of basic necessities – including housing, food and treatment – are covered while people are managing their illnesses and applying for other income support such as DSP.

Targeted employment and employment support programs

Paid employment opportunities for mental health consumers need to involve best practice human resource management. Employees should be able to access support when they need it and should not be discouraged from taking sick leave to deal with their mental illnesses. Employment opportunities should be fulfilling and based on the person's interests, abilities, skills and previous experience; it can be empowering for consumers to know that their employment is not simply about obtaining income.

Social enterprises programs should be promoted and initiated in various community groups as alternatives to mainstream employment. It will build entrepreneurship skills, increase ownership of the program amongst consumers, and promote social inclusion. There are many examples around the world and in various sectors that show how social enterprises have been successful. In 2004 Finland passed the Act on Social Enterprises that defines a social enterprise as being any enterprise that is entered on the relevant register and at least 30% of whose employees have disability or are long-term unemployed. As of May 2010, 154 such enterprises had been registered, the largest with 50 employees.^{3,4}

Social Firms' is another term used in the UK to differentiate their purpose from other types of social enterprise. The specific purpose of Social Firms is to create jobs for people who find it hardest to get them. A 'Social Firm' is a

³ Sociaalinen Yritys (2010). *Social Enterprises in Finland*. Retrieved July 27, 2010 from http://www.sosiaalinenyritys.fi/sofi_english

⁴ Pättiniemi, P. (2006). *Development of legal framework for social enterprises in Finland*. Retrieved July 27, 2010 from <http://www.oecd.org/dataoecd/8/51/37508850.pdf>

market-led enterprise set up specifically to create good quality jobs for disadvantaged people in the labour market.⁵ According to 2010 sector mapping there are 99 existing Social Firms and 82 emerging Social Firms in the UK. Over 1,000 severely disadvantaged people have found paid employment within the sector through Social Firms. It is estimated that someone receiving Incapacity Benefits (disability support pension) who gains full time employment, the Social Firm sector accounts for savings of at least:

- * £30 million in welfare benefits;
- * £8.5 million in health care; and
- * £1 million in social services.

A similar term, Social Firms, is being used in Australia. Social Firms Australia defines it as follows:

A social firm is a business created with the specific purpose of employing people with a disability or other disadvantage in the labour market and to provide a needed product or service. Modifications required for employees in need of support are built into the design of the workplace. Ideally, 25-50% of a social firm's workforce consists of disabled or disadvantaged employees. Every worker, regardless of their disability or non-disability, is regarded as equal and is treated as such, with equal rights and equal obligations.⁶

However as many consumers have remarked, lack of information and promotion as well as their limited availability creates significant barriers to access.

The availability of employment and entrepreneurship opportunities which allow for alternative income support (such as through a disability insurance payment) in times when people are experiencing difficulties in managing their health is important in supporting recovery from mental illness.

Employment support programs should be run based on a recovery approach. This means that the aim of such programs should not always be simply getting mental health consumers into paid employment as quickly as possible, but rather finding what sort of paid employment suits the lifestyle and the recovery of the individual involved.

DSP application simplification

The process for applying for DSP should be simplified, especially for people who are re-applying. This will require straightforward forms and coordination of data.

⁵ Social Firms UK. *What is Social Firm?* Retrieved July 27, 2010, from <http://socialfirmsuk.co.uk/about-social-firms/what-social-firm>

⁶ Social Firms Australia. *Social Firms and Partners*. Retrieved July 27, 2010 from <http://www.socialfirms.org.au/partners.php>

Peer support programs

Mental health consumers who are facing income-related difficulties would greatly benefit from more extensive state-funded peer support programs to assist them to access the support they need.

Remedies which are unlikely to be useful

The Network considers income management to be unlikely to be a useful remedy for the vast majority of people living with mental illness. Income management should only be used in specific circumstances when it is proven to be an absolute need. As the Seven Principles of Personalisation say:

Give me enough help, but not too much; I've got something to contribute too. Disabled or older people, their families and their communities must not be assumed to be incapable of managing their own support, learning skills and making a contribution.

The Network also considers that it would not be of particular use to conduct a review of the effect of Centrelink payments and policies on people with mental illness, or a review of how people with mental illness are faring under current PBS arrangements. The only way such reviews would be constructive is if their scope was to examine how Centrelink payments and PBS arrangement could fit within a personalised budgeting paradigm.

QUESTION 3: OF THESE REMEDIES, WHICH ONES SHOULD BE PURSUED AS A MATTER OF PRIORITY?

The Network considers the following three remedies should be pursued, in order of priority:

1. Personalised budgets;
2. Disability insurance; and
3. Targeted employment and employment support programs.

Of these three remedies, personalised budgets are by far the most likely to ease the income-related difficulties of people with mental illness.

The Network looks forward to seeing constructive advice from the National Advisory Council on Mental Health (NACMH) to the Minister for Health and Ageing, The Hon. Nicola Roxon MP, to improve conditions for people living with mental illness and financial hardship – particularly through creating better, personalised services and a reliable safety net.

APPENDIX 1: THE SEVEN PRINCIPLES OF PERSONALISATION

Right to Independent Living – I can get the support I need to be an independent citizen. If you have an impairment due to aging or disability, which means you need help to fulfil your role as a citizen, then you should get the help you need.

Right to a Personalised Budget – I know how much money I can use for my support. If you need on-going paid help as part of your life you should be able to decide how the money that pays for that help is used.

Right to Self-Determination – I have the authority, support or representation to make my own decisions. If you need help to make decisions then decision-making should be made as close to you as possible, reflecting your own interests and preferences. Advance directives may be used for people with mental health or dementia

Right to Accessibility – I can understand the rules and systems and am able to get help easily. The system of rules within which people have to work must be clear and open in order to maximise your ability to take control of your own support.

Right to Flexible Funding – I can use my money flexibly and creatively. When you are using the personalised budget you should be free to spend your funds in the way that makes best sense to you, without unnecessary restrictions

Accountability Principle – I should tell people how I used my money and anything I've learnt. Both you and the government have a responsibility to each other to explain your decisions and to share what you have both learnt.

Capacity Principle – Give me enough help, but not too much; I've got something to contribute too. Disabled or older people, their families and their communities must not be assumed to be incapable of managing their own support, learning skills and making a contribution.