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Issues Paper Submission

Productivity Commission inquiry into Disability Care and Support

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Psychiatric Disability Services of Victoria's (VICSERV) role

VICSERV is a membership-based organisation and the peak body representing community managed mental health services in Victoria. These services include housing support, home-based outreach, psychosocial and pre-vocational day programs, residential rehabilitation, mutual support and self-help, respite care and Prevention and Recovery Care (PARC) services.

Many VICSERV members also provide Commonwealth funded mental health programs.

VICSERV welcomes the opportunity to provide an initial submission to the Productivity Commission's (the Commission) inquiry into establishing a national disability scheme (NDS). The submission focuses on the needs of persons with a psychiatric disability and their carers in relation to the proposed NDS.

1) Who should be eligible?

It is unclear from the issues paper whether this inquiry is focused on the NDS replacing the whole disability service system, parts of the system or added on to aspects of the existing system. The issue of the scope of the NDS is important as it affects issues of who should be eligible and on what basis.

For the purposes of this submission, VICSERV will frame its submission on the assumption that the inquiry is focused establishing a single system of care.

VICSERV is of the view that all persons with a mental illness should be eligible for assistance under the NDS irrespective of age, type of mental illness or severity of illness. As indicated by the Issues Paper, 25% of disabilities requiring constant or frequent support are those related to mental health. Mental health related disability however is often overlooked in thinking about disability. This is evidenced further by the way in which the Issues Paper is framed with the options focused more on traditional notions of disability.

In this respect, a universal definition of disability needs to be determined and adopted in order to inform eligibility. A good starting point is the International Classification of Functioning, Disability and Health (ICF) as endorsed by the World Health Organisation. The ICF however will need to be applied in comprehensive way to ensure it reflects the realities of persons with a psychiatric disability. Eligibility should be considered within the framework of the social model of disability with a greater emphasis on activities related to relationships, communication and social inclusion.

Determining eligibility under the NDS by the extent of disability is inappropriate in the context of psychiatric disability. Early intervention has been shown to have positive effects in terms of recovery. The earlier that people are able to access the right services, the better the outcomes for the person and their carers. A person with a mental illness may not necessarily be disabled but should have access to appropriate supports and services commensurate with corresponding need.

Cutting-off the scheme to persons who may be experiencing a short-term disability is unworkable due to the episodic nature of mental illness. A person with a mental illness may only experience short-term disability during which they are unable to participate fully in the workforce, education or community more broadly. Access and choice of services during what may be a temporary period of disability again is integral to long-term recovery and reduces the likelihood or severity of future relapse.

¹ Disability Care and Support, Productivity Commission Issues Paper, May 2010, p9

Limiting the scheme to non-age related disability and who is most in "need" is ambiguous and will lead to arbitrary and inconsistent determinates of eligibility with the result being people seeking services missing out. Furthermore, there are differing views as to what an aged related disability is and whether a particular disability is indeed age related rather than late on-set of a mental illness.

The eligibility issue is also important when considering people with varying degrees of different types of disabilities. For instance, a person may have an intellectual disability as well as a mental illness. Each disability when taken on its own terms may be mild in nature and thus would make an individual ineligible under the NDS if the threshold was severe disability. However when taken together (as is the reality), the compounding effects of multiple disabilities may severely impede an individual's social and economic participation.

Recommendations

- 1. That all persons with a psychiatric disability be eligible to take part in the proposed NDS. This scheme should be open to all regardless of age, level of disability or types/levels of "need".
- 2. Persons with short-term disability be eligible to access services under the scheme.
- 3. People should be able to access services commensurate with their individual level of need.
- 4. Assessment processes need to be flexible taking into account the whole person including compounding effects of all aspects of the individual's health including social and economic participation.
- 5. That there be a legislated entitlement for support over lifespan.
- 6. That there be no income means testing or requirement that an individual or their carer plunder their assets before being eligible under the scheme.
- 7. Assessment of need should utilise a variety of assessment tools which respond to the episodic nature of mental illness.
- 8. That a universal definition of disability be adopted with the starting point being the ICF. Psychiatric disability assessment requires greater emphasis on impairments to relationships, communication and social inclusion rather than just core activities such as self care, communication and mobility.

2) Who gets the power?

Self-determination is one of the key principles of Psychosocial Rehabilitation. That is the ability for people to make decisions in relation to their lives at any given time.² VICSERV is of the view that any proposed NDS must have consumer (including carer) empowerment at its core. Empowerment encompasses the autonomy to make choices from a meaningful range of options and to determine for ones self what is best.

Allocating funds to a third person to determine how and when services should be used is disempowering and contrary to the self-determination principle. Disempowerment is debilitating and impedes recovery.

Individualised or consumer directed packages with a whole of life approach is ideal for those who are amenable to this option in that it allows users/and their carers the freedom and autonomy to chose services appropriate for their individual needs. VICSERV however recognises that managing individualised packages is not an option that is appropriate for all and should not be the only option.

² The Principles of Psychosocial Rehabilitation written by Cnaan, Blankertz, Messinger & Gardner (1988) "Psychosocial Rehabilitation: Toward a Definition" in *Psychosocial Rehabilitation Journal* 11(4) were collectively adopted in Vitoria in 1992 by the community managed sector as the foundation of our work with clients with mental illness.

The issues paper raises concerns that allocation of funds directly to the person could lead to people with disability being taken advantage of or funds being spent on "inappropriate" goods or services. However as indicated by the UK experience:

'Despite often-stated fears, the shift to self-directed services did not result in: fraud, misuse of funds; large increases in costs; widening inequalities; users floundering, unsure how best to spend their budgets. ⁸

While there is a very small portion of the community where this is the case, mechanisms such as recognition of advance directives and capacity for supported decision making will go some way in alleviating this concern and honouring the wishes of the individual user of services.

This freedom however can only be fully realised if there are meaningful services options to choose from. Leaving services entirely to the market would diminish the range of available service options available as more and more services go under due to no longer being economically viable. It is important that innovation and growth of services be encouraged under the NDS.

Another aspect of empowerment is the ability to advocate for individual needs. If consumers and carers are truly to be empowered, advocacy initiatives must also be funded.

Recommendations

- 1. Power to determine what services are required should be held by the consumer and/or their carer.
- 2. Individualised packages should be received and managed by the individual at first instance. If the individual is unable or unwilling to manage their own affairs then that power should be delegated in accordance with the individual's advance directives. Further, there needs to be established a capacity for supported decision making particularly where an advance directive does not exist. That is a way in which the individual can be supported to arrive at their own decisions. Costs involved in supported decision making should be borne by the scheme a person who requires assistance in managing their affairs should not be disadvantaged by this need *vis a vis* the scheme.
- 3. Service development and advocacy initiatives must be appropriately funded to provide greater options for persons with a disability and to encourage the consumer and carer perspective whether it be through the NDS or through other funding streams.

3) What services are needed and how should they be delivered?

VICSERV is of the view that before one can talk about the types of services needed and how they should be delivered one must first determine what should be the ultimate aim of services.

The NDS must be orientated towards recovery. A definition of recovery which is adopted by many within the Community Managed Mental Health Sector is articulated by William Anthony⁴ who identifies recovery as:

'. . . a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skill and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the

³ Leadbeater C., Bartlett J., Gallagher N., Making it Personal, Demos, London, 2008, p.13, viewed 11 August 2010 at: www.demos.co.uk/files/Demos PPS web A.pdf?1240939425

⁴ Anthony, W.A. (1993). *Recovery from mental illness: the guiding vision of the mental health service system in the 1990's*. Psychosocial Rehabilitation Journal, 16(4), 11-23.

limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.

In this context recovery can be understood as:

"... a product of dynamic interaction among characteristics of the individual (the self/whole person, hope/sense of meaning and purpose), characteristics of the environment (basic material resources, social relationships, meaningful activities, peer support, formal services, formal service staff), and the characteristics of the exchange (hope, choice/empowerment, independence/interdependence)'6

The NDS must be built upon recovery principles. As Patricia Deegan states:

'Disabled persons are not passive recipients of rehabilitation services. Rather, they experience themselves as recovering a new sense of self and of purpose within and beyond the limits of the disability...Recovery refers to the lived or real life experience of persons as they accept and overcome the challenge of the disability...The recovery process is the foundation upon which rehabilitation services build."

Working with people with psychiatric disabilities in a recovery framework requires a somewhat different skill set than working with other disability types. There is an emphasis working intensively to remove barriers to social inclusion.

Another fundamental basis upon which services should be built is the rights based approach. At the core is the respect for the person's human rights in terms of how services orientated, delivered and used. Adoption of the United Nations Convention on the Rights of Persons with Disabilities, of which Australia is a signatory as the basis upon which the scheme is built is important to realising this aspiration.

When viewed through the lenses of recovery and human rights, the needs of persons with a psychiatric disability are the same as any human being. These needs include:

- 1. Social inclusion;
- 2. Adequate and secure housing;
- 3. Good health outcomes; and
- 4. Meaningful economic participation and education.

The NDS should go some way in supporting people to meet these needs with provision of services which assist individuals (whether consumers or carers) to participate to the best of their ability economically and socially as well as to improve quality of life to an optimal level.

This is the social model of health. It is a framework used by many providers in the Community Managed Mental Health Sector and complements the more clinically focussed model used in other parts of the health system. If the NDS is to be truly successful in achieving recovery and preventing over reliance on services a paradigm shift to the social model of health is required.

However services under the NDS should not be the only solution nor should they be at the expense of innovation and continuous improvement in mainstream housing, health, employment, education and social inclusion services.

⁵ Ibid.

⁶ Mental Health Recovery: what helps and what hinders, p.7, viewed 11 August 2010 at: www.nasmhpd.org/general files/publications/ntac pubs/reports/MHSIPReport.pdf

Deegan, P. E. (1988), Recovery: The lived experience of rehabilitation, Psychosocial Rehabilitation Journal, 11(4), 11–19, p11.

Delivery of services needs to be coordinated and there should be ability for relevant services to "link in" to each other without administrative barriers. Service providers (whether it is clinical, primary health or community services) should, under the NDS, be able to work together in meeting the needs of the consumer and carer.

This brings up a fundamental point that if disability services are to be truly effective they need to revolve around the consumer. That is that services need to go where the consumer lives, to his or her community rather than requiring consumers to fit around services. This shift will overcome geographic and bureaucratic barriers in service delivery.

Fundamental to recovery is secure housing – if individuals accessing the scheme do not have stable accommodation, the NDS will inevitably fail. Clear arrangements need to be made with state jurisdictions to establish and implement an investment plan for increasing supported social housing.

Recommendations

- 1. Services and delivery of those services should be based on a rights based approach.
- 2. Individually tailored packages which are flexible to accommodate the changing needs of the consumer should be the primary way in which services are made available. The consumer (and their carer) should be able to pick which services make up the package.
- 3. Promotion of recovery (based on the definition above) should be at the core of any NDS.
- 4. A coordinated approach must be taken in delivering services with the ability for services to link in to each other easily and efficiently.
- 5. Services should be delivered to the consumer rather than requiring that the consumer accommodate the service provider. This requires an increase in home-based outreach services.
- 6. Arrangements need to be made with state and territory governments for investment in increasing social housing.

4) How should the scheme be funded?

The Issues Paper outlines a number of ways in which the scheme can be funded including an additional Medicare levy, pay as you go schemes, allocation of funding by government, taxation or incentives for carers and individuals to self-fund.

Funding should be through a social insurance scheme that is publicly funded whether it is through an additional Medicare levy or taxation commensurate with earnings. The social insurance funding model reinforces that the responsibility to support persons with a disability falls on the public at large.

Recommendations

1. That a social insurance model funded by an additional Medicare levy or taxation commensurate with earnings be adopted.

5) How should the scheme be organised and implemented?

As indicated above, a collaborative and coordinated approach should be taken in organising the NDS. Implementation should be staged in order to ensure appropriate workforce capacity to meet demand. One of the key issues for the disability sector is retention of staff due in part to the level of pay and lack of developmental opportunities. This indicates that further investments need to be made by federal, state and territory jurisdictions towards workforce training, development and remuneration.

Recommendations

- 1. There should be a coordinated approach in the organisation and implementation of the NDS
- 2. Arrangements need to be in place with federal, state and territory jurisdictions for extra funding to build workforce capacity through greater incentives to join and stay in the disability sector. Creation of developmental opportunities and increase in wages are the key to building capacity, both of which require additional funding.