Disability Care and Support
Productivity Commission Inquiry

August, 2010

NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG)

NSW Consumer Advisory Group – Mental Health Inc.
ABN 82 549 537 349

20th August 2010

Ms Patricia Scott
Presiding Commissioner
Disability Care and Support Inquiry
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

disability-support@pc.gov.au

Dear Ms Scott

Re: Disability Care and Support Productivity Commission Inquiry

The NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) is the independent, statewide organisation representing the views of mental health consumers at a policy level, working to achieve and support systemic change. Our vision is for all mental health consumers to experience fair access to quality services which reflect their needs.

We are pleased to have the opportunity to provide comments on the issues paper regarding the Disability Care and Support Productivity Commission Inquiry.

NSW CAG endorses and strongly supports the purpose of the Convention on the Rights of Persons with Disabilities to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (UNCRPD, 2006). At NSW CAG we know that people living with mental illness have the capacity to live rich and fulfilling lives and contribute to their communities. It is an unfortunate reality that there are various barriers in society that prevent many people from reaching their full potential as active citizens. We are of the view that a National Disability Scheme is a significant step towards realising the objectives of the Convention in practice, resulting in better outcomes for people with disability, including those who experience psychosocial disability due to living with mental illness.

Our submission specifically addresses the needs of people with a mental illness who, as a result of their mental illness, experience psychosocial disability. In particular we are responding to questions regarding:

- Eligibility
- Decision making
- The nature of services
- Workforce issues
- Governance and infrastructure

Our submission also recommends that any service established to support people who experience disability needs to be underpinned by the philosophy of recovery and consumer participation.

NSW CAG would also like to see opportunities for people who experience mental illness to provide further comment once a draft National Disability Scheme is further developed.

Yours sincerely,

Karen Oakley
Executive Officer

Basis of this Advice

NSW CAG exists to ensure that policy makers hear the perspectives of mental health consumers[1] across NSW. To enable our representation of mental health consumers and to advocate for systemic change, NSW CAG elicits information from:

- Over 1000 people on our Network who are accessible via the internet;
- Face to face consultations with consumers within each Area Health Service across NSW.
- Our knowledge base derived from consulting with consumers of mental health services in NSW over the last 17 years.

NSW CAG's comments and recommendations regarding the Disability Care and Support Inquiry are based on such information.

Mental Illness as a Psycho-social Disability

As noted within the Issues Paper, mental illness is recognised as a disability by the World Health Organisation (2009) and within the United Nations Convention on the Rights of People with Disabilities (2006). It is well known that mental illness can have a significant impact on a person's education, employment, relationships, and health (eg. Kitchener, Jorm, & Kelly, 2010). Thus, rather than resulting in physical disability, mental illness can mean that a person experiences psychosocial disability. Indeed, mental illness is amongst the leading causes of disability in Australia (Begg, Vos, Barker, Stevenson, Stanley, & Lopez, 2007).

While it is imperative that mental illness is included within the disability system, it is important to recognise that, like many illnesses there is a spectrum of the disabling nature of the mental illness. Some people with a mental illness may experience little or no disability as a result, whereas others will experience severe or profound disability.

However, unlike many other disabilities, the disabling effects of mental illness may fluctuate. For many people, the symptoms of their mental illness are episodic in nature. People typically experience periods of reduced symptoms and therefore a reduction in some of the associated disability, while at other times symptoms and their disabling effects may be enhanced. It is important that a disability system is designed to be able to meet the fluctuating needs of people who experience psychosocial disability associated with a mental illness.

Any framework developed for the NDS therefore needs to be flexible to meet the individual needs of people who experience psychosocial disability associated with having a mental illness. In this context assessment needs to include all aspects of a person's life situation to measure and identify the type of need that can be met through the NDS.

[1] People who have a mental illness and use mental health services.

NSW CAG also would like to distinguish between the two components of support that are required by psychosocial disability due to mental illness: clinical health needs and disability support needs. In looking at a National Disability Scheme (NDS), NSW CAG believes that the focus should be on providing support relating to the occupational (things that occupy a persons time such as employment, cooking, socialising etc) and social inclusion needs of people rather than the health/clinical needs that should remain the responsibility of the public health system, and other support structures such as the PBS. Having said this NSW CAG realises that there is still a long way to go in terms of improving these systems to ensure they are adequate in meeting the needs of people who experience mental illness.

NSW CAG also advocates that the NDS:

1. Caters for the needs of both individuals who experience a psychosocial disability as a result of having a mental illness and where relevant respite for family and carers separately.
2. Assesses the level of psychosocial disability experienced by a person and caters for this based on need.
3. Ensures that assessment processes for mental health problems under the NDS include everyone applying to the scheme. NSW CAG is aware that many people with physical disability are also at risk of developing a mental health problem which needs to be considered in their support needs.

Principles informing the development of a NDS

In order for an NDS to be successful in meeting the needs of people who experience psychosocial disability from mental illness, it needs to be underpinned by the principles of recovery and consumer participation. These principles can be applied to all disabilities and services.

Recovery Oriented Service Provision

The concepts of “recovery” and “recovery oriented service provision” (see appendix A) have been promoted within mental health services for some time (eg. Commonwealth of Australia, 2009; NSW Department of Health, 2008). However, these concepts are just as applicable to the whole disability services spectrum, and provide a sound philosophical basis for the development of a NDS. Basing a system on recovery ensures that services are individualised and holistic, where the individual with the disability is placed at the centre of their care, treatment and service needs. It also bases the system on the participation of people with a disability. In this style of service, care is directed by the individual consumer.

Recovery and recovery oriented service provision are grounded in human rights, respect for individuals, social inclusion, participation, and individuality; these core tenants are reflected within the *Disability Care and Support Productivity Commission Issues Paper* as needing to be incorporated with the disability system.

An in depth explanation of recovery and how concepts of recovery are translated into practice can be found in Appendix A. While the concepts of recovery are incorporated to some extent within the practice of person-centred planning and services, recovery encapsulates a broader approach to service delivery.

Concepts of recovery require that such a scheme needs to be:

- Flexible to individual needs
- Provide choices in support options
- Be person centred
- Provide hope for a person's future

The responses provided by NSW CAG to the key questions posed by the Productivity Commission in the *Issues Paper* will be reflective of a recovery approach to the system.

Consumer participation

NSW CAG promotes that consumer participation is an essential principle that must underpin the National Disability Scheme. Consumers need to have the opportunity to participate in all decisions regarding their treatment, support, and assessment processes.

It must be recognised that each person is unique, and will therefore have different responses and needs regarding how they would like to participate.
We regularly hear that consumers want the opportunity to participate in all situations relating to their treatment and care (NSW CAG consumer consultations, 2009). Indeed, participation is a key human right. The World Health Organisation's *Declaration of Alma-Ata* states that "people have the right and duty to participate individually and collectively in the planning and implementation of their health care" (1978, p.1).

In line with this NSW CAG advocates strongly that consumers participate in each stage of the development of the NDS prior to its implementation.

Improved knowledge about mental illness and advocacy services for people who live with mental illness

A National Disability Scheme needs to be complemented by a significant change in community attitudes and knowledge about mental illness.

Mental health literacy is the knowledge and beliefs about mental disorders which aid in their recognition, treatment and prevention (Jorm, 2006, p.40). NSW CAG hears in our day to day interactions with consumers that there is much work that needs to be done to increase knowledge about mental illness within the health system, community services, workplaces, service providers – both government and non government, and the wider community. Consumers regularly report a lack of understanding of the effects of mental illness, resulting in them experiencing stigma and discrimination (NSW CAG consumer consultations, 2009).

NSW CAG also advocates that the scheme caters for an independent service which provides individual advocacy for people who live with mental illness. Advocacy services, particularly advocacy at an individual level for with mental illness is extremely limited in availability within NSW. NSW CAG often receives requests for access to individual advocacy for people using mental health services. This is a clear gap within current service provision.

Specific Comments on the NDS

1. Eligibility

NSW CAG recommends that the National Disability Scheme:

- **has no age restrictions**
- **provides universal coverage**
- **covers psycho-social issues rather than clinical needs**
- **be based on need**
- **be tailored to individual's needs**
- **provide separate coverage for meeting consumer needs, and for families/carers**
- **covers the whole spectrum of mental health problems**
- **be flexible and accessible for people to increase and decrease support provided based on their need at the time**

Is need the appropriate basis for eligibility?

NSW CAG believes that need is the appropriate basis for eligibility. However, we believe that it should be based on disability and social support needs rather than clinical needs which should continue to be covered by the public health system.

NSW CAG believes that all individuals who are experiencing psycho-social disabilities as a result of their mental illness should be eligible for assistance under the National Disability Scheme. In assessing eligibility, the Scheme also needs to be designed to account for the episodic nature of mental illness, and the related disabilities. For this reason, it is important that such a scheme allows people with a mental illness to 'step in' and 'step out' of the supports provided through the Scheme in a timely manner as and when the need arises.

NSW CAG does not agree that 'severe or profound' disability is an appropriate criterion for assessment. NSW CAG believes that the need for support should be identified by the psycho-social support needs of the individual. Rather than being based on the medical diagnosis or symptomatology, eligibility needs to be assessed based on the impact that the illness has on the person's life, and their ability to participate in society.

Who should be in the new scheme?

NSW CAG believes that anyone experiencing a psycho-social disability should be eligible for the scheme, regardless of age, type of condition, when or how they developed a mental health condition, and the resultant psychosocial disability.

What groups have the highest needs or have been most disadvantaged by current arrangements?

Whilst many people are disadvantaged in various ways, NSW CAG is particularly aware of issues facing people in rural and regional areas. Consumers in these areas report heightened levels of isolation and increased difficulties in building social support networks and accessing disability related services.

Again this is exacerbated where a person experiences a dual condition (see below).

Age Limits

The discussion paper raised the question of age as a limitation on the program. NSW CAG does not believe that there should be any cut off on eligibility based on age. The mental health issues of older Australians are well known, with many conditions developing in the later part of life. Depression is widely known to impact upon older Australians, with studies finding that 8.2% of Australians over 60 experience clinically significant depression (Pirkis et al., 2009) and amongst Australians over 65 years, mental illness has a prevalence of 6.1% (Andrews, Hall, Teesson & Henderson, 1999). Women in particular face many mental health risks as they age. Women, unlike men, experience a late onset period for schizophrenia between the age of 45 and 50 (Häfner, Hambrecht, Löffler, Munk-Jørgensen & Riecher-Rössler, 1998; Häfner, 2003). Meanwhile, during menopause, up to 20% of women report experiencing depression (Soares, 2004). The onset of obsessive compulsive disorder and panic disorders also rise at this time (Lochner et al, 2004; Claudia et al, 2004). During menopause, women who have previously experienced a variety of mental health conditions, from bipolar disorder to panic attacks, can also experience a worsening of symptoms and negative effects around this time (Claudia et al, 2004; Marsh, Templeton, Ketter & Rasgon, 2008).

NSW CAG believes that it is not beneficial to the individual or to the community, to cut off support at arbitrary age limits at a time when many individuals may begin to need this additional support for the first time. There are also significant concerns about what would happen under such a scheme when a person reaches this age limit and is suddenly cut of from eligibility for supports to keep them socially connected and working in the community. It would be financially ineffective, and unethical to simply withdraw support and services to an individual, that they, their family or carer, access to improve quality of life. This is also significantly out of line with the philosophy of recovery.

How does need overlap with core activity limitations or other criteria for identifying the severity of disability?

In assessing needs, the disability scheme also needs to ensure that presumptions about people's circumstances are not made, but that the individual, and their family, support networks or service providers are all consulted to accurately understand a person's circumstances.

NSW CAG is aware that some people may have family or strong social networks supporting them, however, it should not be presumed that people with such support are not in need of assistance. Likewise, the NDS should not assume that a person without such support is in greater need.

Which groups are most in need of additional support and help? – most disadvantaged/have highest needs?

Our consultations have revealed that there are several gaps in service provision for people with complex needs. In particular, people with comorbid illnesses such as those who have a mental illness and intellectual disability, those with mental health

problems and physical illnesses, those with substance use and mental health problems and those who experience more than one mental illness. The high incidence of comorbidity surrounding mental illness highlights the need for holistic, coordinated service provision, including broad communication between treating services. It is necessary that the Strategy outlines ways that complex needs can be addressed, including the adequate provision of staff with specialised training.

People from rural and remote areas in particular also require additional support due to the challenges associated with accessing services. It is recommended that more assistance is provided to this population group to provide additional support particularly for transport, interpreter, service access and information technology needs.

2. Decision Making

NSW CAG recommends that a National Disability Insurance Scheme provides:

- Opportunities for consumers to make decisions on the type of support they require
- Advisory support
- Information in an accessible format
- Avenues for consumers and carers to make independent decisions related to their separate needs.

How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong?)

NSW CAG believes it is crucial that consumers are given the key role in decision making over their own support needs. This includes giving them control over funding, choices between services, and an obligation from service providers to take individual needs into account.

The importance of choice makes NSW CAG concerned about the commissions suggestion that people may not be able to spend the money on things *"not usually associated with addressing disability – for example, attending a gym class"* (2010; 23). To address psycho-social needs, consumers require a vast array of options, rather than limitations, on how they spend their money. It should not be in the scope of this scheme to dictate to someone what activities would best meet their needs. For example, physical exercise and the development of social and community networks are well regarded as ways to address, and improve, the impact of mental illness and in that regard, gym classes would be a high effective way to address this (Dimidjian & Davis, 2009; Daley, 2008). This is further consistent with the philosophy of recovery.

> *You know the real practical things that help you get better. Meditation, gyms, I can't do any of them because I can't afford them.*
> (NSW CAG, Consumer Consultation, 2010)

An easily accessible and consumer focused advice service is also required to assist consumers who may need support with negotiating the system and making decisions about their finances.

> *Empowering people rather than telling them what to do. Need to assist people in how to do it rather than doing it for them. For me personally that has been a massive thing in allowing me to make decisions for myself.*
> (Consumer Consultation; 2009)

Factors affecting how much support people get and who decides this.
NSW CAG believes that those conducting assessments and making decisions about payments need to be qualified professionals such as a Social Worker or Occupational Therapist, who also have specific training in mental illness and the impact this can have on a person's life (Refer to section on assessment processes within "Nature of Services"). The professionals conducting the assessments also need to be trained in the philosophy of recovery.

One factor that should be specifically taken in to account regarding the level of support people receive is their location, for example, whether they are living in rural and regional areas. Psychosocial disability experienced by this population is compounded by the lack of regular, suitable services in their areas. Consequently people are forced to pay for transport to larger towns or cities where regular support can be obtained.

It may also be that the scheme funds consumer access to technological facilities to enable access to support via video link.

In addition to this people from culturally and linguistically diverse backgrounds will require additional support in accessing information, interpreters and services.

Should individualised funding include the capacity to save some of the annual payment for future purchases of services or borrow from future payments to pay for current services?
NSW CAG supports the idea of consumers being able to save some of their annual payment. Whilst a 'cap' may be implemented on the total amount they are able to save, having this ability allows consumers to make long term plans and look to purchase items that would normally be unobtainable. Having an allowance for saving also ensures consumers spend their money on needs rather than spending under a "use it or lose it" structure.

What are the risks of individualised funding and how can they be managed? What guidelines would be appropriate? How would any accountability measures be designed so as not to be burdensome for those using and overseeing the funding?
In developing the scheme, processes need to be designed so that consumers have as much control as possible over their finances. Consumers are experts of their own experience and are best placed to identify areas in which they require the most support. It is also acknowledged that there will be some people who may need support in managing the funds obtained through the scheme, or who will be

vulnerable to exploitation and financial abuse by others. NSW CAG advocates that even in such circumstances, the recipient should remain active in the decision making process and that independence, autonomy and flexibility remain the key goals for administration of finances.

NSW CAG also recommends that mechanisms need to be in place to ensure that all recipients of the Scheme should be well informed about the nature of the scheme, and the services that are available to them.

How would individualised funding work in rural and remote areas where service availability is poorer?

Funding structures need to be implemented that encourage disability support workers to live and work in rural and remote areas. Such structures may be similar to the ATAPs and Better Access Scheme models, where workers can access funding to provide a particular service or it may be modeled on a system that provides higher funding to people who work in rural and regional areas, with bonuses to encourage long term work so that consumers can have continuity of care.

Encouraging employment in this sector and supporting members of the public to take up employment assisting people with disabilities will also have the benefit of providing jobs in rural and regional areas.

NSW CAG recognises that some consumers living in regional, rural and remote areas face difficulties due to low service provision. For this reason, NSW CAG advocates for location to be taken into account when assessing a person's need and level of cover under the Scheme. NSW CAG also considers the option that consumers living in regional, rural and remote areas may be entitled to a higher level of payment to compensate for the additional expenses they face in terms of transport costs or information technology resources to communicate with the wider community.

Are there ways other than individualised funding that empower people with disabilities and their families?

NSW CAG is aware that stigma and discrimination towards mental illness is still very strong in society. In consultations with consumers, we frequently here stories regarding negative attitudes and discrimination experiences in workplace, educational settings, government services and community settings.

Stigma towards people living with mental illness can also result in self stigmatisation[2] and family stigma[3], which is equally debilitating (Carr & Halpin,

[2] Self-stigma receives less attention in research and literature than stigma, but can be just as devastating for those with mental illnesses. *Like Minds*, the newsletter of the New Zealand campaign to end stigma, has noted two definitions for self-stigma: "negative thoughts or feelings towards yourself based on the fact that you have a mental illness" and "self-belief in negative stereotypes that have become linked to the experience of mental illness" (Like Minds, Like Mine Project, Apr/May 2007, p. 2)

[3] Family stigma is the prejudice and discrimination experienced by individuals through associations with their relatives. Research has found that this form of stigma can have a significant impact on the families of people with mental illness (Larson, Corrigan, 2008).

2002, p.11). Our consultations provided many comments relating to this, for example one person stated *"the way many psychotic illnesses are perceived in society leads sufferers to stigmatising themselves and hiding away from society".* This results in many people not disclosing their mental illness, which can impact on participation in society. It can also be a difficulty in many situations when the individual is unwell, for example in social settings and in the work place.

The current lack of public education translates to limited knowledge and unfounded beliefs by many about the causes of mental illness, how to seek help and how to access information. This results in confining available support to professionals (Jorm, 2000), and can also act to reinforce stigma and discrimination within the community. Comments from consumers included that there is a *"lack of awareness in the community that mental illness can be transient, non-violent"*, and that it is the *"lack of mental health literacy which contributes to ignorance, misconceptions and lack of understanding".* NSW CAG also hears regularly of stigmatising and discriminating attitudes that are present by staff in health care services themselves.

This can also result in reducing the attraction for people to work within mental health related fields such as disability support programs.

Individualised funding will be beneficial in providing consumers with the resources to participate in society, but this needs to be complimented by a society that welcomes them to participate. This can only be achieved through increased education and awareness.

Therefore, NSW CAG strongly believes that the Government needs to invest in an anti-stigma and awareness raising campaign to shift social attitudes regarding mental illness. We also advocate that this program includes targeting workplaces, to encourage employers to provide flexible and supportive work environments to people with mental illness.

> *As soon as you say you have a mental illness you get treated with no dignity – get treated as you're a scrap heap. Is there a code of conduct on how we should get treated?*
> (NSW CAG, Consultation, 2009)

> *I will not disclose my mental illness in the cover letter but in the interview you will. You know you won't get a call back and it's very disheartening. You are sort of discriminated. When you say what you've got you see their face change*
> (NSW CAG, Consultation, 2009)

Carers

NSW CAG recognises that some people who experience mental illnesses, have carers, and for this reason, there needs to be funding within the National Disability Scheme that can be accessed purely by carers to cover the cost of expenses such as carer respite.

It is important that funds are made available specifically to carers as research shows that carers have low levels of health and personal wellbeing and that many carers suffer from, or are at risk of depression and anxiety (Cummins, 2007). By ensuring that carers have the resources to fund respite and assistance, this will improve the longevity, and quality, of the care that they provide.

NSW CAG believes that it is important for carers and consumers to have separate funding so that decisions about their own needs are made by them wherever possible.

Mechanisms also need to be put in place to ensure that consumers and their carers have full access to information and service provider details, so that informed decision making can occur.

Having specific funding to support carers also acknowledges the financial barriers that they face, such as at times having to take significant amounts of time out from work to provide support to family members who experience mental illness.

3. The Nature of Services

NSW CAG recommends that the National Disability Scheme focuses on:

- Social support and inclusion
- Life skills
- Occupational skills
- Skills for independent living
- Personal development
- Education
- Personal support services
- Financial assistance for transport needs particularly for people in rural and remote areas
- Financial support
- In home and community respite
- Employment assistance and support
- Range of options for employment
- Early intervention
- Community anti-stigma campaigns and education

NSW CAG also recommends that:

- All people conducting assessments for the NDS are well trained in mental health, and its psycho-social implications.

It is clear to NSW CAG that the services provided under the National Disability Scheme should be clearly related to the disability needs of individuals, and not their clinical needs. Clinical needs should continue to be met under the health system.

As discussed, NSW CAG recognises that improvements need to be made to additional systems, such as the health systems and transport systems and the PBS to assist people with mental illness, but we believe that these improvements need to be made under these independent structures and not through the NDS.

Services not currently provided that should be part of a national disability scheme

Individual Advocacy Service

NSW CAG is aware that the lack of a state-wide individual advocacy service in NSW is a significant gap in service provision to people with mental health problems. People frequently report issues with liaising and negotiation with Government services such as Centrelink, Community Services, the justice system or Housing NSW, as well as with the private agencies, such as banks, electricity companies and other service providers. Many consumers also report that an individual advocate would be of great assistance in negotiating the education system, health system or systems where they wish to make a complaint and feel that they are not being listened to.

Such an advocacy program assists consumers who feel that they are not able to make themselves heard; who feel that they are experiencing discrimination, or whose mental health and life experiences make it difficult for them to engage with authority figures.

This form of assistance would assist in alleviating anxiety and stress normally encountered in such processes, and would place consumers in a much better position to fully participate in society.

> *People need to be able to advocate for themselves by having meetings with all levels of the hierarchy without fear of repercussion compromising their care*
> (NSW CAG, Consultation, 2009)

> *You need an advocate on your side to achieve anything*
> (NSW CAG, Consultation, 2009)

Social Supports

A lack of social supports and activities has been raised as a problematic issue for people living with mental illness. Social isolation is a contributing factor to mental illness, and the protective effects of social ties and supports in reducing vulnerability are well documented (Herrman, 2001, p.710; Brissette, Scheier & Carver, 2002). Many consumers with whom NSW CAG has liaised with have found activity centres and group outings an essential component to coping with the challenges associated with mental health problems. Suggestions provided from our network include the creation of clubhouses and camps as recreational facilities and activities.

Issues identified include:

- Lack of peer support networks: People during our consultations have made various comments, including that “the biggest barrier is feeling utterly alone … wondering if you would survive and not being given information about the support available” and that “living in a rural town there are no real supports for me”.
- Lack of social activities and recreational centres.
- Lack of social support networks, resulting in many people living with mental illness firstly accessing crisis support as no other supports are available. Therefore higher numbers of people are getting to the point of needing crisis services in situations that may have been prevented through stronger support from social networks.
- Mental health problems are not limited to occurring in work hours; however services are structured in this way, leaving many people isolated outside of this time. There is a strong need for twenty four hour access to non-crisis support.

To what extent, if any, should people be able to cash out the benefits from a basic service/appliance and use it as a part payment in purchasing a premium service?

NSW CAG supports the idea of a scheme that allows people to “cash-out” the benefit from a basic service that they are entitled to as per their assessment, and use this as a contribution towards higher level services. It is important that the key part of this Scheme’s framework is the flexibility for people in identifying and affording their needs and priorities. For this reason, any mechanisms that enable choice and flexibility should be included within the Scheme.

Through the National Disability Scheme, individuals with need should be able to access services such as:

- Individual advocacy
- In-home and community respite
- Employment assistance and support
- Range of options for employment
- Early intervention
- Community anti stigma campaigns and education

Should assessment gauge both eligibility and the extent of need in the one set of instruments, or should the assessments be distinct?

NSW CAG believes that the assessment structure should be designed in such a way that they provide flexibility to the applicant. They need to be tailored so that the assessment of eligibility and need can be made in one sitting if the consumer finds it difficult to get to appointments, or finds multiple appointments stressful. Additionally, they should be able to be conducted in two separate sessions, without affecting the assessment process, if the consumer finds lengthy sessions difficult.

NSW CAG is also concerned that the use of particular assessment tools can be problematic if applied to people with a distinct range of issues. Previous assessment tools that have been used by a variety of programs often poorly capture the needs of people with mental illness as they are skewed towards

assessing physical or intellectual disabilities (Harries, Kirby, Nettelbeck & Taplin; 2005; 28). Any tool that is adopted needs to adequately meet the needs of people experiencing a mental health conditions.

NSW CAG believes that the assessment tool adopted should also assess for mental health problems being experienced by anyone accessing the scheme. Many people experiencing other forms of disability may be experiencing an undiagnosed mental illness, or, the impact of the mental illness may be overlooked by other types of disability. For example, mental illness in people with intellectual disorders are 3-5 more times common than in the general population (Cooper 1997; Gustafsson 1997). Thus, the adaptation of current tools to adequately cover people with a mental illness would be preferable to ensure one tool is being used consistently, and to reduce the number of assessments a person has to undertake.

Assessment Process

Assessment needs to be conducted by a qualified professional such as a Social Worker or Occupational Therapist, who also has specific training in mental illness and the impacts it has on a person's life. As stigma and discrimination related to mental illness has a strong presence in the community it is essential that the people conducting these assessments are also well trained to understand the impact that mental illness can have on quality of life. NSW CAG regularly hears that professionals placed in such positions often have a limited understanding of mental illness, leading to stigma and discrimination. Those conducting the assessment should also have a strong understanding of the recovery perspective and ensure that recovery principles underpin their assessment process.

> *No one was telling me what was going on. I knew something was going on. A lot of people I have spoken to have felt that we have done nothing wrong, we only have mental illness but I was made to feel like I was a criminal*
> (NSW CAG, Consultation, 2009)

> *I found that the companies contracted to help me 'overcome my barriers to employment' were useless, insulting, rude and stigmatising.*
> (NSW CAG, Consultation, 2010)

NSW CAG believes that the assessment process should contain self assessment components, as well as avenues for medical specialists, family, carers, and support providers to be involved in this process.

In addition, assessments should be conducted in an environment flexible to the person's needs. In some cases, this may mean the assessor will be required to attend the person's home.

It is also imperative that whilst assessments need to be thorough, the turn around time for approving eligibility needs to be as short as possible, to alleviate stress and anxiety during this time.

How could the capacity for people to move between services – both intra and interstate – be made easier?
The system needs to be flexible and available nationally so that it ensures people living in remote locations close to state borders have their support needs met based on practicality and not limited by state boundaries. NSW CAG is regularly made aware of the impact that state boarders can have on people with travel time being significantly increased in cost and hours due to not being eligible for a service that is just across the state boundary.

4. Workforce Issues

NSW CAG recommends:

- **Raising the base wage of people working in disability support services**
- **Anti-stigma and discrimination programs are implemented throughout Australian workplaces.**
- **Incentives are offered to encourage qualified people to work in rural and regional areas.**
- **Mental health training is made available to interpreters**
- **All people employed within the sector undertake Mental Health First Aid as a minimum qualification**

How can workers be attracted to the industry? What role should government play in this process?
The insufficient disability support workforce in regional, rural and remote areas of NSW is of significant concern to NSW CAG. Issues related to consumers going without access to support or respite, or having no choice or continuity in which professional they are able to see regarding their support needs, are frequently raised at our consultations.

NSW CAG believes that the industry would benefit if the government acted to raise the base wage of people employed in the social services sector. In addition, making the obtainment of qualifications in the disability sector more affordable and accessible would also be beneficial.

Again, demystifying mental illness through a mental health literacy campaign would reduce stigma and discrimination by the community and therefore attract more people to want to work in this area.

NSW CAG advocates for incentives to be developed that encourage people to work in the disability sector, and in particular, in rural and remote areas. This may involve scholarships that encourage allied health students to specialise in disability support, or scholarships that require trained support workers to spend time working in remote, rural and regional areas at the completion of their training.

NSW CAG believes that it is also necessary to ensure that mental health and disability related issues, including the impact of stigma and psycho social

disabilities is specifically included in the curriculum of all relevant tertiary education programs, including allied health programs, nursing and medical.

What role should government play in upgrading the skills and training opportunities available to workers?

One area in particular where consumers indicate skill upgrading is required is in regards to interpreters. Some interpreters are not well educated about mental health issues which can result in the translation of inaccurate or confusing information. For this reason, NSW CAG advocates for specific training and education to be provided to interpreting staff and services, and that culturally and linguistically diverse (CALD) clients being entitled to request a mental health trained interpreter.

NSW CAG also believes that the government should increase training opportunities available to CALD persons and Aboriginal and Torres Strait Islanders, to increase their involvement in this sector, and assist in filling serious service gaps to these clients groups.

It would also be beneficial to explore options for providing subsidies to non-government organisations to increase the number of staff that can be sent on training programs and conferences to develop their professional skills and knowledge in mental health.

NSW CAG advocates for all workers in this sector to undergo:

1. Education on recovery oriented practice
2. Training and education around the effects of stigma and discrimination on people who live with mental illness, their families and carers, including education around appropriate language use
3. Training around consumer participation, its value and how to incorporate it into practice
4. Continued workforce training around culturally appropriate responses, communication and treatment, focusing on the needs of Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse communities.
5. Workforce education on promotion, prevention and early intervention of mental illness.

What types of skills and workers are required?

Consumers indicate to us that they want workers who are qualified, but who are also able to treat them as individuals, and provide them with flexible, recovery orientated support that meets their personal needs. Consumers want workers who are willing to build relationships with them, encourage them to take the lead in their life, and utilise strong communication skills to ensure that consumers, and their families and carers, have a strong understanding of mental health issues, and support options.

NSW CAG also believes that within the context of the NDS, it is important that all staff within the public health setting receive appropriate training in the NDS so that they can assist consumers to access the scheme.

What is the appropriate level of training required before commencing work in the industry? Should existing certification requirements be altered to reduce obstacles to people working in the disability sector?
NSW CAG is concerned that altering certification requirements may reduce the quality of education and training received by people employed in the disability and mental health sector. NSW CAG believes that quality of skills and knowledge should not be compromised in an effort to increase the workforce size. Rather, access to obtaining qualifications needs to be improved particularly for people living in rural and regional areas.

NSW CAG believes that Mental Health First Aid should also be a compulsory component of training for anyone employed in the disability sector.

What role is there for national accreditation?
National accreditation would be advantageous in that, just as an NDS scheme would aim to make it easier for consumers to shift between localities or states, qualified staff would also be able to transfer their skills to other service providers with greater ease, ensuring retention of quality staff.

National accreditation also means that consumers can then expect the same level of support and training, from workers, regardless of where in Australia they reside.

5. Governance and Infrastructure

NSW CAG recommends that

- **People with mental illness are represented on any advisory board for the scheme**
- **Information about the scheme and entitlements are made available through a wide range of resources, including the internet and face to face options. These need to be in an accessible format.**
- **Any reviews of the scheme are primarily based on consumer experiences, with the views of carers and families also being considered.**
- **Strong relationships are formed between the NDS, NGO sector, mental health services and GPs.**
- **Processes for consumer evaluation of the NDS are in place and easily accessible**
- **Complaints processes are in place that are easy to access, with support provided for people who wish to make a complaint. Processes are required to ensure a timely response from the NDS to the consumer that addresses their concerns.**

The structure of the NDS needs to be simple for people to navigate with multiple options for how they can access it. Information needs to be in an accessible format both written in print, on the internet and via face to face consultation with a case coordinator (see below) of the Scheme.

In considering mental illness within a disability support system, it is important that there are strong relationships and connections with local mental health services. This includes non-government services funded by health departments and General Practitioners. This is important to ensure a consistent approach to the person's support and recovery journey.

How can we reduce the need for form filling and unnecessary re-assessment?

To minimise re-assessment and excessive form filling, consumers should be allocated a continuous case coordinator who remains their contact person, and consequently, is familiar with their needs. The impacts of staff turn-over need to be carefully monitored and ensure smooth transitions, rather than ad hoc staff allocations. A plan needs to be developed between the case coordinator and consumer that is revisited according to the consumer's needs.

How would stakeholders be given a 'say' in a national disability scheme? Who should be represented?

People with the lived experience of mental illness should sit on any board, advisory group or representative body of the board and be involved in the Scheme from the top level.

Processes for consumer participation to input into policy development and decision making processes also need to be availed.

NSW CAG considers that it is imperative that people living with mental illness are involved in all aspects of monitoring the National Disability Scheme. This is in line with the Australian Government's social inclusion agenda, and National policy within health and mental health regarding consumer participation (eg. Australian Health Ministers, 2003). A range of mechanisms need to be put in place to ensure that consumers have genuine opportunities to be involved in this monitoring. It is crucial that people living with mental illness be represented on committees and in consultations that serve this purpose. A framework for consumer participation also needs to be developed for evaluation of the NDS and services that are provided under it. NSW CAG recommends that consumers have input into and are involved in all aspects of quality improvement to do with the Scheme. Further mechanisms may include:

- Working with mental health consumer non-government organisations, consumer networks and organisations to reach a wide audience of those with experience of mental illness, and gaining their feedback in this way;
- Online feedback, which could be in form of surveys or feedback forms;
- Consultations and information sharing sessions;
- Evaluation forms and information needs to be provided in an accessible format, keeping in mind different literacy levels, and visual and cognitive difficulties associated with mental health medication.

What arrangements should be in place for making complaints?

Any complaints process needs to have options for both written and verbal submission, and support provided in submitting complaints. Verbal submission is particularly important due to the fact that there is a high rate of low literacy levels

amongst people who experience mental illness, and the side effects of many medications which can impact on people's vision and ability to write effectively.

Complaints need to be dealt with and responded to in a timely manner. Should a complaint be taking time to resolve it is important that consumers remain informed of what is happening with their complaint and expected timeframes for a response.

How would people find out what they were entitled to?
People should be able to find out about their entitlements from a range of options. The concept of a 'one-stop-shop' model can be quite useful for consumers, as the ability to meet with someone face to face to look over options is very valuable. However, this needs be supported by easily accessible information in different formats such as the internet, brochures and over the phone options. This is particularly relevant for people living in regional, rural or remote areas who do not necessarily have easy access to "one-stop-shop" models.

Internet and written materials are also insufficient alone, as many consumers can not afford to access the internet. Many consumers also face difficulties in utilising written materials due to low literacy levels, and the side effects of some medications impacting on people's vision.

NSW CAG believes that it is necessary for service providers, such as public and private mental health workers, Social Workers or Psychologists, who may be providing regular assistance or treatment to Scheme users, to be well trained in the Scheme so that they can assist and guide Scheme users to access options. Effective training of service staff will ensure that, in essence, no consumer will encounter "wrong doors" or incorrect information, when seeking assistance.

When and how would a national disability scheme be evaluated?

NSW CAG believes that an evaluation process for collecting feedback on the scheme needs to be established at its implementation phase. The formal evaluation should then be conducted after the first five years of implementation.

In doing this NSW CAG advocates that the evaluation process is underpinned by strong consumer participation processes, including providing users of the scheme the opportunity to provide their perceptions and experiences of it. This will allow identification of what is and isn't working well under the scheme. This process needs to ensure that the different needs of people with various disabilities, including mental illness, are taken into consideration when conducting the evaluation.

Implementation Issues
How will stakeholders be engaged during implementation, including their input into a scheme and in raising awareness of how to use a new scheme?
Consumers should have a place on any board or committee relevant to the implementation of the Scheme, to ensure that all decisions about implementation are guided by its recipients.

A public promotion campaign is needed to raise awareness about such a Scheme which includes many different types of media including television and the internet. This also needs to inform the public of who is covered under the Scheme, including the mention of people who experience mental illness.

6. Other comments:

NSW CAG is also concerned about the financial disadvantage experienced by people who are moving between the Disability Support Pension (DSP) and employment. Once a person receiving the DSP commences work of up to fifteen (15) hours or more, they lose their entitlement to their pension and the Centrelink health care card. This can cause exceptional difficulties in affording medication and participating in the community for people who experience mental illness.

Appendix A: Recovery and the Translation of Concepts of Recovery into Practice

This is based on NSW CAG's response to the Australian Mental Health Services and Programs' Development of Recovery Principles. It therefore also contains wording derived from the Australian Mental Health Services and Programs' Draft Recovery Principles, which were adapted from the Hertfordshire Partnership NHS Foundation Trust Recovery Principles in the UK.

Recovery is about a journey that is a unique and personal experience for each individual. It has often been said to be about: gaining and retaining hope, understanding of ones abilities and limitations, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self. Essentially, recovery is about a life journey of living a meaningful and satisfying life. For some people recovery may mean experiencing an absence of symptoms. For many, it is about finding meaning and living a satisfying life while still experiencing symptoms and/or being in treatment. Sometimes people with a mental illness become unwell, and their quality of life is not what they would like it to be. This does not mean that they are no longer on a journey of recovery. Rather, they are at a different point in their journey.

In conceptualising recovery from a personal perspective, it is about the journey of life; of learning, growing in understanding about ones self and the world, setting goals and working towards them, changing goals as life changes, and seeking a meaningful and satisfying life. Every experience, positive and negative is therefore a part of the individual's recovery journey.

The role of services in recovery is to provide an environment where a person can work towards their goals with the support they need. Below are ways in which recovery can be operationalised within service delivery.

1. Individual uniqueness:

Recovery oriented practice:

Recognises that recovery is not necessarily about cure but is about living a meaningful and satisfying life.

Accepts that recovery outcomes are personal and unique for each person.

Goes beyond an exclusive health focus to include an emphasis on all aspects of their life.

Empowers individuals to be at the centre of the care they receive.

All care and service provision is a collaborative and interactive process.

Encourages individuals to direct their own recovery journey, using their own experience as a guide

2. Individual Driven Journey:

Recovery oriented practice:

Sees the individual as part of the solution.

Supports and empowers people to make choices about how they want to lead their life and acknowledges choices need to be meaningful to the individual and creatively explored.

Supports individuals to build on their strengths, resilience and experience and take as much responsibility for their lives as they can at any given time.

Ensures that there is a balance between duty of care and support for people to take positive risks and make the most of all opportunities.

Provides a variety of support and treatment options.

Ensures access to information about different service options.

Ensures people have the opportunity to develop plans to inform interventions if and when they become unwell.

3. People's rights:

Recovery oriented practice:

Involves listening to, learning from and acting upon communications from the individual, their relatives and others about what is important to each person.

Promotes and protects people's human rights, including social, cultural, political and economic rights.

Supports the individual to develop and maintain meaningful social, peer, recreational, occupational and vocational activities which enhance mental wellbeing.

Instills hope for a person's future and ability to live a meaningful life.

4. Dignity and Respect:

Recovery oriented practice:

Consists of being courteous, respectful and honest in all interactions.

Involves sensitivity and respect for each individual's own values, culture, spirituality, gender and age.

Challenges discrimination and stigma whether it exists within services or the broader community. This also includes identifying and challenging internalised stigma that may be experienced by the individual with a disability.

View the person as a whole, and not as an illness or disability.

Acknowledges shared humanity and the life experience of all people.

Respects that people have their own beliefs and interpretations of disability and works with these.

All service provision is a collaborative and interactive process.

5. Partnership, Relationships and Communication:

Recovery oriented practice:

Acknowledges each person is an expert on their own life and that recovery involves working in partnership with individuals, their relatives and carers to provide support in a way that makes sense to them.

Values the importance of providing information in a format that is accessible to the individual to enable effective engagement

Involves working in positive and realistic ways with individuals, their families and carers to help them realise their own hopes, goals and aspirations.

Acknowledges the importance of continuity of care. Services and staff therefore build relationships with other services to ensure that links between services are made and continuity of care is achieved.

6. Evaluating Recovery Oriented Mental Health Practice:

Recovery oriented practice:

Ensures and enables evaluation of recovery oriented practice at several levels.

Services seek the individual's experiences of care and this is used to inform quality improvement activities.

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