What we know:
The consumer perspective on mental health reform in NSW

Working Paper – October 2013
The Mental Health Commission of NSW has received a significant amount of information from consumers, consumer organisations and the peak body for people with a lived experience of mental illness NSW Consumer Advisory Group – Mental Health (NSW CAG) about what consumers want the Commission to focus on.

This paper is to set the scene about what we know and have learned from conversations with consumers over the past 12 months. Some of the themes and suggested areas for change have shaped the approach outlined in the Towards a draft Strategic Plan for Mental Health in NSW – the Life Course and the Journeys paper. This paper is included in your Consultation Pack and can also be found on the Commission website.

The focus areas that we will cover in this paper are:

- Living well in the community
- Inpatient care
- Forensic care
- Criminal justice

**Living well in the community**

**Adequate income and access to employment**
Employment and adequate income is central to people feeling valued and valuable. The Commission wants to further explore the influence of work and community participation on consumers’ lives and this has been reflected in the journey Towards a Better Life within the Life Course Journeys paper mentioned above. Towards a Better Life means that people with a mental illness have opportunities to gain and maintain employment and are not reliant on the Disability Support Pension or other government payments.

Consumers have recommended the introduction and extension of targeted workplace campaigns and support for workplaces to equip them to employ and support people living with mental illness.

**Education and training for workplaces**
Consumers have told us that they believe education and training about mental illness should be provided to employers and co-workers, to reduce stigma and discrimination in the workplace.

**Drop-in centres in the community and capacity building**
It is widely recognised that it is important for all people to feel appreciated, accepted and respected by people in their community and be able to participate and contribute meaningfully. Some consumers have told us that a safe place to go and to meet with other people who have similar experiences to them was central to their recovery. We have also heard from consumers that when there is no community drop-in centre, neighbourhood centre or clubhouse in their town they have felt more isolated because there is nowhere to go. Consumers in regional NSW also told us they know empty buildings that could be used as clubhouses but they don’t know how to go about getting funding to start them up.
Consumers have recommended that the Commission focuses on ways to increase access to safe spaces that consumers can go and hang out and have a cup of tea and chat or participate in education or activities.

Consumers also recommend helping GPs and other clinicians to understand what is available in the community. Often clinicians are aware of clinical services but not about other support services or consumer-run groups.

**Stable housing**
A home is important for everyone and often people who have a mental illness experience difficulties in gaining and keeping a place they can call home. NSW CAG has recently undertaken ‘No place like home’ consultations about this topic which the Commission was grateful to be able to participate in. We heard stories from people about their difficulties around housing and in particular housing that they felt was safe, secure and where they could live for a long time. Some people had faced discrimination by real-estate agents who knew they had a mental illness and refused them a lease on this basis. Some people who lived in housing provided through Housing NSW or social housing cooperatives said they felt scared of their neighbours because they used drugs and alcohol and could be violent.

The Commission will look closely at the recommendations that come from the extensive consultations undertaken by NSW CAG through the “No place like home” project when they become available.

**Community transport options**
Getting around town, attending appointments, and visiting friends and family are often seen as fundamental to a person’s participation in the community and their own health. Particularly in regional areas there may be few transport options, and their cost may be prohibitive. Consumers have expressed to us that they want transport options that meet their needs particularly in smaller regional towns.

**Consumer participation**
Consumers recommended that the Commission invests in mechanisms that support consumer participation on an individual, service and systemic level. The Commission values the experience of consumers and is committed to ensuring that increased participation of consumers at all levels is central to the work of the Commission.

Consumers have consistently expressed that one of the best strategies for participation is through paid employment. As part of this approach, the Commission will include strategies to increase and support the consumer workforce (Peer Workforce) in the draft Strategic Plan for Mental Health in NSW.

**GPs and mental health care**
Consumers tell us that often their GP is the person best placed to provide them with mental health care and monitor their medication. Some consumers however have said their GP doesn’t know enough about mental illness, medications or the side effects of medication to be able to provide this support.
Consumers recommend that the Commission advocate for greater investment to support GPs to provide mental health services.

**Early intervention across the lifespan and across the state**
Consumers consistently report that the current services are focused on crisis intervention rather than trying to prevent people becoming unwell.

Consumers recommend shifting away from a crisis system to a proactive community-based system. This shift requires an increased investment in community-based services to distribute them more equitably across the state so that everyone has the opportunity to get help when they need it.

**Recovery-oriented services**
Consumers want the Commission to look at innovative ways of supporting a culture shift towards recovery-oriented services and investigate other ways of working, including examining the role that peer-run services can play.

Consumers also want the implementation of the National Recovery Framework to be closely watched and monitored at a state level.

**Inpatient care**

Hospital admission can be traumatic and consumers say they do not feel they always have a therapeutic outcome. The lack of choice of hospital and treating team, and the lack of control over the use of seclusion or restraint, play a large role in the disempowering experience of going to a psychiatric unit. Consumers recommend the Commission support initiatives that eliminate restrictive and coercive practices.

Consumers tell us that where possible the health system should be looking at how people could be supported outside of the hospital environment. Sub-acute units which can act as a "step up" from the community or a "step down" out of hospital are models that might be useful to avoid acute inpatient stays.

Consumers have also told us that the triage process through the emergency departments is sometimes very traumatic. Staff in the Emergency Departments are generally not trained in mental health and can tend to avoid contact with consumers. Some consumers have told us that they are supervised by security guards rather than receiving care from nursing staff and that this is intimidating and not of any therapeutic benefit.

**Forensic care**

A very small proportion of people who commit crimes are found not guilty by reason of mental illness. These consumers are called forensic consumers or forensic patients. The forensic mental health system comprises both in-patient and community services. Sometimes there are not enough forensic beds available in hospital and a forensic consumer might remain in jail until a bed becomes available. Consumers say this can be very frightening.
Consumers have provided feedback to the Commission about areas that could be improved in the forensic mental health system. They include having a multidisciplinary team available at each unit or a community team that includes a peer worker and an education coordinator or occupational therapist. Consumers say that staff should respect forensic consumers’ views and experience, and actively involve people in their own treatment and care decisions, including discharge care planning.

There should be a process for forensic consumers to be able to provide feedback to the service. The Mental Health Consumers Perceptions and Experience of Services (MH-CoPES) framework could be part of forensic services’ process for continual quality improvement. Forensic consumers say they should have the same rights as other consumers to be linked to community programs and schemes that will help them when they return to the community.

**Criminal justice**

Consumers say that interactions with the police can be terrifying. Often when consumers have contact with the police they are very unwell and the experience of being restrained and treated like a threat to society can be very shameful. Mental illness shouldn’t be a reason to treat someone like a criminal. Consumers say that more police need to be trained in mental health, especially police in rural and remote areas where police and ambulance are often the only form of transportation to hospital. The Commission knows that the NSW Police are committed to further training for police officers and will maintain a keen interest in this activity.

**The road ahead**

This is not an exhaustive list but we wanted to make sure that you know that we are aware of some of the current issues faced by consumers. We want the conversations that you have about the draft Strategic Plan for Mental Health in NSW to be solution-focused, aspirational, and bold in nature.

In five years time, what would services and supports for people who are experiencing mental distress look like?