IN CONCLUSION
We want mental health system change that makes a real and positive difference in people’s lives. We want to see the evidence of high-quality, person-centred approaches to wellbeing and mental health support spread across the spectrum of activities and services – not only health but also social supports, housing, employment, education, justice and many others.

We need to know that the commitments we make to this kind of change can be monitored and measured, so that we can acknowledge, reinforce and reward positive progress. At the same time as scoping and designing reforms we must devise the measurements that will tell us whether these reforms are succeeding. This includes evaluating people’s experiences and how they fare in the longer term on their recovery journey. A mix of quantitative and qualitative data will be required to give a comprehensive picture.

We are working against a backdrop of previous reform initiatives that have been energetically pursued but not fully realised, which in turn have engendered some scepticism and fatigue. As we work towards reform, we need to continue to build the consensus for change at the same time as implementing it. Robust measurements, that are tracked over time, publicly reported and relate to things we really care about, will help us achieve this.

Agencies, organisations and mental health workers will need additional skills in information management to support expanded data collection activities. Extension of existing data linkages between government agencies and the community-managed sector will be necessary to produce a meaningful, nuanced picture of the lives of people who experience mental illness, and their support needs across many domains of health and social services.

All monitoring work should be guided by the lived experience of people with a mental illness, their families and carers. We must design structured, evidence-based ways to evaluate the success of services in meeting their needs. This means measuring not only the quality of the services, but their capacity to support positive change more broadly. This includes how well they integrate with other services, whether they support local decision making, and their capacity to retain their quality and remain true to their principles and objectives as they grow.

The Commission’s approach to measuring, monitoring and reporting will:

- be guided by the lived experience of people with a mental illness, their families and carers
- support reform and drive positive changes in the mental health and wellbeing of the people of NSW, at both individual and community level
- support agencies to work collaboratively to improve mental health and wellbeing
- identify priorities for further research
- contribute to better informed public debate.
A PERSONAL POINT OF VIEW

Consumer and carer experiences of care and support are not an optional extra. They should be central to our evaluations of services, and to the choices we make about the things we measure, monitor and report on.

NSW is already one of the first jurisdictions to have a framework for involving consumers in improving public adult mental health services. MH-CoPES (Mental Health Consumer Perceptions and Experiences of Services) questionnaires invite people to say what they liked as well as what needs improvement in the services they use. But response rates and use of the survey vary across the state.

The current questionnaire is being further developed as a national measure which will allow comparison with other states and territories.

The Commission is leading a project to develop new methods of data collection and reporting mechanisms, including the use of tablets, text messages and online surveys that allow people to offer real-time feedback in hospitals, clinics, the community and from home. It is hoped that by enabling people to contribute timely perspectives more easily, more people will participate and their collective insights will be more representative of the views of all consumers.

There is currently no continuing survey of the experiences of families and carers of people who live with mental illness. The NSW Carers (Recognition) Act 2010 provides impetus to look in more detail at carer experiences, and to use these to inform policy.

Consumer and carer input will also be essential in designing measures to evaluate the effectiveness of support and services. Those measures should not simply be derived from information that is already routinely collected. The measures should address things people tell us they care about, which may relate not only to health but also to social connectedness, ability to work or study, or any other aspect of the recovery journey.

TELLING EVERYONE

Information about the quality and performance of mental health support systems should not be a secret. Anyone in the community should be able to find timely data that can help inform their decisions as consumers, carers, professionals, sector managers or researchers. This should include data on the performance of individual services.

We should insist on regular public reporting of mental health data and statistics that are compatible with other data collections, support further analysis and interpretation, and are presented in ways that are accessible to all the community.
WHAT ARE WE MEASURING

The Commission will use and, where necessary, develop measures and indicators that address the actions and overarching reform focus of the Strategic Plan, as well as the mental health and wellbeing-related targets and actions set out in the State Health Plan and NSW 2021.

The Commission supports the following monitoring initiatives and will align its activities with them.

- The national targets and indicators for mental health reform endorsed by the Council of Australian Governments Expert Reference Group, which address six foundation areas:
  - More people with poor mental health will have better physical health and will live longer
  - More people have good mental health and wellbeing
  - More people with poor mental health will live a meaningful and contributing life
  - More people will have a positive experience of support, care and treatment
  - Fewer people will experience avoidable harm
  - Fewer people will experience stigma and discrimination.

- The Mental Health Non-Government Organisation Establishments National Minimum Data Set, which is being developed in partnership with Australian Institute of Health and Welfare.
  - In NSW, in 2011 the non-government sector accounted for 6% of state government spending on mental health, and it is expected community organisations will take on a growing role under reforms intended to minimise reliance on hospitals. It is essential in this environment that we can measure how well both small and large community organisations perform in supporting people and their recovery. The minimum data set is intended to support the collection of nationally consistent information on the activity of community managed organisations that provide mental health support, to better inform policy, practice and planning. It is scheduled for implementation in 2015-16.
People are not their symptoms. And yet the system has been dominated by the idea that mental illness is the inevitable outcome of a person’s particular chemical make-up. This in turn has evoked chemical and diagnostic responses, almost exclusively.

While diagnosis and medications have a place in our kit, we also need other tools and strategies that position an idea of mental wellness around a person – a whole person with a history, a family (or not), living in a community.

The development of a strong, proud, peer workforce, thoroughly integrated into our mental health and social support systems, is the best way to support the creation of the tools we will need to bring about the enormous change required.

People with a lived experience of using mental health services, or of being directly subject to the Mental Health Act through involuntary treatment, are in an excellent position to provide a safe relational environment for others.

Peer workers can support decision making with the person but can also support clinicians seeking to enhance the decisions they make with the wisdom of lived experience. In both cases, the person’s expertise – supported by the peer worker’s experience – remains at the centre of decision making.

This provides greater agency and increases skills to pursue recovery, not only for the person but also for the system, which has much to learn from engaging people living with a mental illness.

People who engage with our mental health services are managing their lives as best they can. Most have experienced abuse as a child or at another age. Sadly, practices still exist in the mental health system that can revive the memory and experience of trauma for vulnerable people: seclusion is one, the gross overuse of mandatory community treatment orders another.

People whose lives are diminished by the effects of unresolved interpersonal trauma are often the same people who don’t engage in the mental health system because they are frightened to do so.

People with mental health challenges also engage, or not, in services for families, justice and other areas of health. Supporting them effectively in the face of their previous traumatic experiences is a system-wide challenge. It requires tools that can effect change towards wellbeing in social, emotional, physical, cognitive and cultural realms, across all areas of service delivery.

It will require hard work – very hard work – to make these changes happen, but that is what we must ask people to do: the hard but valuable work of personal, interpersonal and system recovery.

“...to make these changes happen ... the hard but valuable work of recovery.”
The Commission would like to acknowledge and thank the more than 2,000 people who contributed to the development of the Strategic Plan for Mental Health in NSW, to which this Report is a companion.

In particular we wish to recognise the many people with a lived experience of mental illness, and their families and carers, who generously assisted us in the planning process and helped us to remain true to our central mission: to develop policies that promote and protect mental wellbeing, and support people who experience mental illness to live well in our community.

The Plan presents reform actions that have the potential to make a real difference in people’s lives. But we also wished to honour the inspiring stories we heard during the Plan’s development phase. In this Report we have attempted to portray those human experiences and to present mental health reform from the perspective of those who stand to benefit from it.

Many organisations and individuals also contributed professional knowledge and expertise. We would like to acknowledge particularly the members of the Commission’s Community Advisory Council, whose energy, insight and diverse perspectives are reflected on every page of these documents, and Synergia Ltd who provided the Commission with valuable assistance in the development of the Plan. NSW Consumer Advisory Group - Mental Health (NSWCAG) and Mental Health Carers ARAFMI NSW (ARAFMI) reached out to their networks of consumers and carers on our behalf and encouraged people to contact and engage with us. We are truly grateful for their trust.

The following organisations and individuals assisted us in many different ways, from hosting discussions in country community halls to providing specialised technical advice.

Aboriginal Affairs NSW
Aboriginal Disability Network
Action Foundation for Mental Health
Aboriginal Health & Medical Research Council of NSW
ACON
Adults Surviving Child Abuse
Afford Employment
Aftercare
Ambulance Service of NSW
Anglicare Northern Inland
Anglicare NSW South, NSW West and ACT
Association of Psychologists in Developmental Disability Services
Auburn Diversity Services
Australian Association of Social Workers
Australian Drug Foundation
Australian Foundation for Disability
Australian Institute of Business Wellbeing
Australian Institute of Criminology
Australian Medicare Local Alliance
Australian Red Cross
Australian Psychological Society
Mr Eddie Bartnik, former WA Mental Health Commissioner
Beautiful Minds
Benelong’s Haven
beyondblue
Billabong Clubhouse
Black Dog Institute
Blue Mountains Tenancy Advice and Advocacy Service
B Miles Supported Accommodation
Booroongen Djugun Aboriginal Corporation
Bourke Aboriginal Health Service
BoysTown
Bradfield Park Carers Program, Kirribilli
Brain and Mind Research Institute
Break Thru People Solutions
Broken Hill Youth Accommodation and Support Service
Butterfly Foundation for Eating Disorders
Canadian Mental Health Association
CanTeen
Carers Assist NSW
Carers NSW
Catholic Community Services NSW/ACT
Centacare New England North West
CentaCare Wilcannia – Forbes
Central Coast Local Health District
Centre for Rural and Remote Mental Health
Centre for Translational Neuro-Science and Mental Health
Centre of Research Excellence in Mental Health and Substance Use
Centre of Research Excellence in Suicide Prevention
Co.As.It. (Italian Association of Assistance)
Community Relations Commission for a Multicultural NSW
Community Restorative Centre
Community Solutions
Consumer Activity Network (Mental Health)
Council of Social Service of NSW (NCOSS)
CRANES Community Support Programs
Create Foundation
Crescendo Partners
Corrective Services NSW
Department of Developmental Disability Neuropsychiatry (3DN) – University of NSW
Department of Education and Communities
Department of Family and Community Services
Department of Police and Justice
Department of Premier and Cabinet
Disability Advocacy NSW
DiverseWerks
Drug and Alcohol Multicultural Education Centre
Durri Aboriginal Corporation Medical Service
Dubbo Aboriginal Land Council
Dubbo Koori Interagency Network
Professor Kathy Eagar, Director, Australian Health Services Research Institute Sydney Business School – University of Wollongong
Elizabeth Evatt Community Legal Centre
Ethnic Communities Council of NSW
Executive Evolution
Fairfield Migrant Resource Centre
Far West Local Health District
Far West Medicare Local
Federation of Ethnic Communities Council of Australia (FECCA)
Future Achievement Australia
Gamarada Indigenous Healing and Life Training
Gay and Lesbian Rights Lobby
General Practice NSW
GROW NSW
headspace
Healing Foundation
Health and Disability Commission New Zealand
Health Education and Training Institute
Mr Ravy Heng, Khmer Carers Support Group, Cabramatta
Hills Holroyd Migrant Resource Centre
Homeless Person’s Legal Service
Homelessness NSW
Housing NSW
Hunter Institute of Mental Health
Hunter Medical Research Institute
Hunter Medicare Local
Hunter New England Local Health District
Hunter Valley Research Foundation
Illawarra Multicultural Forum
Illawarra Shoalhaven Local Health District
Immigrant Women’s Health Service
Independent Community Living Australia
Indigenous Australians with Mental Health Disorders and Cognitive Disability in the Criminal Justice System Project – University of New South Wales
Inner West Tenants’ Advice and Advocacy Service
Inner West Sydney Medicare Local Interrelate
Jarrah House
JewishCare
Justice Health & Forensic Mental Health Network
Juvenile Justice NSW
Kamira Alcohol and Other Drug Treatment Services
Kangaroo Valley Carers Support Group
Kogarah Diagnostic Assessment Service
Lane Cove Council
Launchpad
Lebanese Muslim Service
Legal Aid
Life Without Barriers
Lifeline
Lifeline Foundation for Suicide Prevention
Lifeline Harbour to Hawkesbury
Liverpool Migrant Resource Centre
Lou’s Place
Maari Ma Health Aboriginal Corporation
Macarthur Diversity Services Initiative
Macedonian Welfare Association
Manly Drug Education and Counselling Centre
Professor Maree Teesson and colleagues, Centre of Research Excellence in Mental Health and Substance Use, National Drug and Alcohol Research Centre – University of New South Wales
Marrin Weejali Aboriginal Corporation
Professor Bernadette McSherry – University of Melbourne
Mental Health Association NSW
Mental Health Carers ARAFMI NSW
Mental Health Coalition of South Australia
Mental Health Commission of Western Australia
Mental Health Coordinating Council
Mental Health Review Tribunal
Metro Migrant Resource Centre
Mid Mountains Neighbourhood Centre, Katoomba
Mid North Coast Local Health District
Milk Crate Theatre
MIND Australia
Mission Australia
Multicultural Communities Council of Illawarra
Multicultural Disability Advocacy Association of NSW
Multicultural Problem Gambling Service
Murrumbidgee Local Health District
Murrumbidgee Medicare Local
National Aboriginal and Torres Strait Islander Suicide Prevention Advisory Group
National Disability Services
National Drug and Alcohol Research Centre
National Mental Health Commission
National StandBy Response Service
Neami National
Nepean Blue Mountains Local Health District
Network of Alcohol and Other Drug Agencies
New England Medicare Local
New Horizons Enterprises
Northern NSW Local Health District
Northern Settlement Services
Northern Sydney Local Health District
Northern Sydney Medicare Local
NSW Agency for Clinical Innovation – NSW Intellectual Disability Network
NSW Attorney General’s Department
NSW Audit Office
NSW Bureau of Crime Statistics and Research
NSW Commission for Children Youth and Families
NSW Consumer Advisory Group
NSW Council for Intellectual Disability
NSW Education Program on Female Genital Mutilation
NSW Health
NSW Institute of Psychiatry
NSW Kids and Families
NSW Ministry of Health
NSW Ministry of Police
NSW Multicultural Health Communication Service
NSW Multicultural Health Services
NSW Ombudsman
NSW Police Force
NSW Public Guardian
NSW Public Service Commission
NSW Refugee Health Improvement Network
NSW Refugee Health Service
NSW Rural Fire Service
NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS)
NSW Treasury
Occupational Therapy Australia – NSW Division
Official Visitors Program
On Track Community Programs
Parents, Families, and Friends of Lesbians and Gays
Parramatta City Council
Partners in Culturally Appropriate Care NSW and ACT
People with Disability Australia
Pharmaceutical Society of Australia
Pioneer Clubhouse, Balgowlah
Polish Australian Welfare Organisation
Post and Antenatal Depression Association (PANDA)
Professional Association of Nurses in Developmental Disability Australia (PANDDA)
Psychotherapy and Counselling Federation of Australia
Public Schools NSW
Queensland Mental Health Commission
ReachOut.com by Inspire Foundation
Redfern and Waterloo Aboriginal Community
Mr David Richmond
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REFERENCES

WHAT WE KNOW


Infographics


ABORIGINAL WELLBEING


Infographics


THE REFORM STORY


BEYOND THE CITIES


Infographics

A QUESTION OF DIVERSITY


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Infographics


HEALTHY BODY AND MIND


Infographics


INTELLECTUAL DISABILITY


Infographics


A MATTER OF JUSTICE


Infographics


DRUGS AND ALCOHOL


**JOURNEY 4 – HEALTHY TRANSITIONS**


**Infographics**

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**JOURNEY 5 – TOWARDS A BETTER LIFE**


**Infographics**


**JOURNEY 6 – BREAKING THE CYCLE**


**Infographics**


**JOURNEY 7 – BODY AND SOUL**


**Infographics**


JOURNEY 8 – LIVING LONG AND STRONG


Infographics


ARE WE GETTING THERE?


