



National Register and National Mental  
Health Consumer and Carer Forum  
Annual Workshop

2010 Workshop  
**Issues and Outcomes Report**

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*Prepared by Edwina Deakin  
Principal, EJD Consulting and Associates  
Workshop Facilitator*

**Mental Health Council of Australia**

**Tel: 02 6285 3100**

**Fax: 02 6285 2166**

**Email: [kim.harris@mhca.org.au](mailto:kim.harris@mhca.org.au)**

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## **1) BACKGROUND**

### **1.1 About the National Register and National Mental Health Consumer and Carer Forum (NMHCCF)**

In 2007, the Mental Health Council of Australia (MHCA) established the National Register of Mental Health Consumer and Carer representatives, utilising funding provided by the Department of Health and Ageing.

National Register consumer or carer representatives are available to be members on advisory and other committees, boards, planning or evaluation groups or to perform other advocacy roles. Register members use their lived experiences, understandings of the mental health system, and communication skills to promote the issues and concerns of consumers and carers in a broad range of contexts at local, regional, state as well as national levels.

In 2010 the National Register has 55 mental health consumer and carer representatives with experience of mental health training, advocacy, policy development, communication or in other fields requiring leadership or representation of consumer and carer issues.

MHCA has hosted an annual workshop since 2008, to enable members of the National Register to learn from each other, and to develop new skills and understandings to make them more effective advocates.

In 2009 and 2010 NMHCCF members also attended the workshop. The NMHCCF is the combined national voice for consumers and carers participating in the development of mental health policy in Australia.

### **1.2 About the 2010 Workshop**

The 2010 Workshop Program is included at Attachment A.

On 29 and 30 April 2010, the MHCA convened the third National Register workshop in Melbourne.

The overarching theme of the 2010 workshop was human rights. Numerous presentations and discussions focused on how the rights of mental health consumers and carers could be strengthened, particularly in the face of current challenges and threats.

The relevance of the United Nations Convention on the Rights of Persons with a Disability was also a recurring theme of the workshop.

Fifty four (54) individuals participated in the two-day workshop. This included:

- 46 members of the National Register and/or National Mental Health Consumer and Carer Forum comprising representatives from all states and territories, plus various national representatives. There were:

- 10 representatives who were also workshop presenters; and
- 6 representatives who were workshop moderators or facilitators.
- 5 external speakers.

The two day workshop program was developed with feedback from Register members, building on evaluation feedback from the 2008 and 2009 Workshops. The Program was designed to:

- 1) Broaden participants' understanding of current policies, practices and directions in mental health across Australia
- 2) Expand participants' confidence, capacity and skills in their work as consumer and carer representatives
- 3) Provide opportunities for peer support, information exchange and networking between participants, including those who work in other states and territories
- 4) Identify any joint issues that should be actioned in order to better support consumers and carers in the future.

Day 1 of the workshop program included various scene setting presentations on the theme of human rights. This included a keynote presentation from Graeme Innes AM, the Disability Discrimination Commissioner.

The program included four break-out sessions that enabled participants to contribute to small-group settings. Day 1 topics included:

- Systematic Advocacy: How to change the mental health system
- Cultural Issues in Mental Health, with a specific focus on working with Aboriginal and Torres Strait Islander consumers and carers
- Mental illness: A young person's illness
- Participatory Action Research and its use in service evaluations

Day 1 also included a plenary discussion on current research and why consumer and care participation in research is so important.

Day 2 of the workshop extended the discussion of human rights and included a keynote address by Patrick McGorry, 2010 Australian of the Year and Professor of Youth Mental Health at the University of Melbourne. There was also a presentation by Tony Fowke in his role as President of the World Federation of Mental Health.

The plenary discussion on Day 2 focused on recovery practices, plus two break-out sessions on the topics of:

- Stigma and Discrimination
- Employment Opportunities for Consumers and Carers

What follows is a summary of key issues and outcomes discussed by participants during the 2010 Workshop.

## 2) KEYNOTE PRESENTATIONS

On each day of the workshop there was a keynote presentation:

### **Graeme Innes AM, Disability Discrimination Commissioner**

*Graeme focused on "Rights" and provided a practical discussion of rights under the Disability Discrimination Act and the United Nations Convention on the Rights of Persons with Disabilities (called the DisCo).*

Key issues and actions arising from Graeme's presentations included:

- In 2008, Australia ratified the DisCo and in so doing committed the country to ensuring and upholding the rights of people with a disability to live without discrimination and to take all appropriate measures to eliminate discrimination.
- Some of the key actions arising from the DisCo include:
  - Promoting research
  - Promoting aids to allow individuals to participate
  - Providing training to people who work with people with disabilities
  - Raising awareness in the community about people with a disability
  - Collecting information about how the above is proceeding
  - Establishing a complaints process to allow people to raise issues.
- A key mechanism for this last provision is complaints to the Disability Discrimination Commissioner.
  - Currently one in every two complaints to the Commission is successful.
    - The process involves the complaint, an investigation, where possible a conciliation, or if warranted a court action.
  - People with mental health issues who feel they have been discriminated against should make a complaint to the Commission
  - All complaints (are anonymously) reported on. They can have powerful impacts on changing industry and government practice
- It was noted that Victoria has its own complaints system similar to the Human Rights Commission.
- Recently the Australian Government has rejected the advice of the Brennan Inquiry to establish a Bill of Rights. Instead it has established a \$12 million Human Rights Framework which includes an education program.
  - There are opportunities for mental health consumers and carers to ensure that some of this funding is allocated to preventing discrimination and stigmatisation.

**Patrick McGorry, Australian of the Year, Professor of Youth Mental Health at the University of Melbourne, and Clinical Director of ORYGEN Youth Health**

*Patrick focused on the shortcomings of the mental health system in Australia and the need for significant reinvestment and reconfiguration given the scale of unmet need particularly amongst young Australians.*

Key issues and actions arising from Patrick's presentation included:

- There are around 4 million Australians affected by mental illness. Of those:
  - Two-thirds receive no treatment at all
  - One third do receive treatment, though often too late and of inadequate quality.
- Currently the national mental health budget is \$5 billion dollars. In April 2010, the Government announced additional funding though this is nearly all focused on the hospital system
  - Australia needs a lot more funding spent on mental health
  - A specific focus needs to be funding for youth services as 75% of mental ill health appears before the age of 25.
- In arguing for more funding, there needs to be a shift in the language we use:
  - Preferred term is mental ill health.
- The evidence and argument for more mental ill health funding is compelling:
  - People with mental ill health have much poorer health outcomes
  - They generally smoke more
  - They generally have poor access to mainstream health services and so problems worsen before treatment can be provided
  - Suicide rates are high, with over 2000 people per year. (This figure doesn't include a suspected 15% in under-reporting)
  - The cost of not funding mental health is enormous.
- The preferred model for mental health funding is not to top-up hospitals and 'board a sinking ship'; nor is it to only support community based services. The preferred model is to look at transformative reform that is suited to twenty-first century circumstances.
  - headspace is a good example of what is needed. It provides young people with access to a one stop shop service for young people and provides:
    - General practitioners
    - Counsellors
    - Youth workers
    - Vocational advisors
    - Alcohol and other drugs counsellors, plus
    - Mental health professionals
  - A stepped approach to care is vital. We do not want people only able to access one type of treatment and support and not able to access another if that is what will make the difference. A stepped care approach offers:
    - Multi-faceted services, and not just clinical solutions
    - Age appropriate surrounds and locations that make individuals feel comfortable and non-stigmatised

- 24 hour service as people do not have a crisis only between 9 am and 5 pm. (We do not run ambulance services only in business hours, so why do we offer mental ill health services this way?)
- Access to treatment in a timely manner and as early as possible
- Through-care as people can relapse and they need to know they will be provided with sustained treatment, building on previous experiences
- Access to affordable housing and residential options. This is not just for acute care, but as part of a step up-step down model of support.
- In addition to new models, there needs to be open discussion of mental ill health in the community. This is needed in order that:
  - We can better recognise young people who need help
  - Family and friends provide a supportive, non-judgemental response when mental ill health issues emerge.
- Optimism and recovery based approaches are vital. These need to be underpinned by a rights based perspective as people with mental ill health have the right to access quality care, including in mainstream settings and should not be treated as second class citizens.
- Early intervention is not just about new consumers. It means support and treatment:
  - Early in life
  - Early in illness
  - Early in episode.
- The solutions are known. We know what works and what is needed. We need models that can provide psycho-social support, as well as good clinical support when needed. This is most likely to come about if all parties work together, and include the voices of consumers and carers who are currently not receiving a fair deal in Australia.

The workshop also included an address by **Tony Fowke**, in his position as **President of the World Federation for Mental Health**.

- The presentation provided a brief history of the Federation and its members which comprise mental health non-government organisations from around the world.
- While the Federation receives some funding from American philanthropic organisations, plus modest membership fees, the organisation currently operates on the voluntary contributions of time and labour by its executive members.
  - The Chief Executive Officer retired in August 2009 and the position has not been filled as yet.
- A key focus of the Federation is to ensure mental health consumer and carer issues are considered in international discussions on health and community development. Person-centred approaches, which focus on the consumer first and foremost and not on the service system, are a key driver of the Federation's activities.
- Other useful principles include the five goals of living sustainability and humanely:
  - Free of hatred
  - Free of worry
  - Live simply
  - Give more
  - Expect less.

### **3) SMALL GROUP WORKSHOPS & PLENARY SESSIONS**

Across the two days of the workshop a total of 6 small group workshops were held, plus two plenary sessions. (See Attachment A for details, including the names of presenters and moderators).

What follows is a summary of the key issues or actions arising from these activities.

#### **▪ Systemic Advocacy (5.1)**

*The goal of this workshop session was to allow participants to explore systemic advocacy and consider:*

- *What is it for?*
- *How is it used?*
- *Who can use it?*

Key issues and actions arising from **Patrick Hardwick's** presentation and the discussion following included:

- Recognition that there is depth of experience and skills amongst Australian mental health consumers and carers, including those attending the workshop
- Representing others is also first and foremost about representing oneself, and using one's own lived experiences. As such it is generally important for consumers to advocate on consumer issues, and carers to advocate on carer issues.
- The mental health system can be daunting, but there are opportunities to advocate and to bring about change.
  - There is long history of consumer and carer systemic advocacy in Australia, much of it stemming from the formation of specific groups such as:
    - VMIAC in Victoria (1982) and ARAFMI in the 1970s, plus the various mental health peaks around Australia.
    - In general there are many more opportunities to advocate now than previously.
- Some key issues to consider include:
  - There are lots of ways of advocating for change including:
    - Writing submissions
    - Convening or speaking at forums
    - Being a member of a committee
    - Advocating with key decision makers or members of parliament etc.
  - It is preferable to:
    - Have key arguments and issues written down as these can have a life beyond the initial airing or meeting
    - Identify solutions as well as problems; this could make change easier
    - To know your material extremely well (e.g. the Mental Health Act or specific policies and procedures)

- It is preferable to know the issues better than those you are advocating to; it strengthens the argument.
  - Listen carefully to counter-arguments and try to take other people's responses into account
  - Good support structures, networks of like-minded people or a formal coalition around issues can be invaluable
    - These need to be drawn on when an issue grows or where other tactics are needed
    - It is hard to advocate on one's own and should be avoided otherwise people can suggest it is just a personal view being expressed
    - Need to ensure that advocates manage their own stress and personal health issues; burn-out is always a risk.
  - Important to ensure information arising from advocacy is shared with other parties and that there are quality opportunities for debriefing.
  - How do you motivate individuals and groups to change and to become empowered in the process
  - Sometimes small changes and victories can be powerful first step towards more important changes.
  - **Cultural Issues in Mental Health (5.2)**
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*The goal of this workshop session was for participants to gain insight into cultural factors that could be seen as indicators of mental illness within Aboriginal communities. The session also aimed to identify some strategies in working and caring for Aboriginal people with an actual or perceived mental illness.*

Key issues and actions arising from **Brendan Church's** presentation and the discussion following included:

- Aboriginal and Torres Strait Islander (ATSI) people have significantly shorter life expectancies than non-ATSI Australians. Currently there is a 17 year gap. They also face:
  - High levels of racism (including internally with Aboriginal communities)
  - A range of social disadvantage and social justice issues
  - Various legacies of colonisation practices
  - Difficulties accessing required services and support (in part due to the mistrust of mainstream services).
- Post Traumatic Stress Disorder is prevalent in many Aboriginal communities. This is associated with:
  - Past removal practices
  - Loss of culture and dislocation from traditional lands and community members
  - Compounding effects of grief and loss
  - Intergenerational disadvantage issues
  - Abuse of alcohol and other drugs.

- Current mental health assessments and diagnostic practices are often very problematic to Aboriginal consumers. For example:
  - They rarely involve family members
  - There is a lot of misdiagnosis
  - Other challenges include:
    - Duplication of services, which can create confusion in the community. For example one service thinking another is dealing with health issues or vice versa and, as a result, individuals falling between the gaps
    - Overmedication or self-medication
    - Under resourcing of some of the most accessible services
    - Management capacity of some services
- When dealing with Aboriginal people with mental health issues it is important to have the family and community involved
- Biological, psychological and social factors also interplay and impact on working with Indigenous individuals and communities
- One solution is to use culturally appropriate assessment tools. Examples include WASC Y, WASC A, IRIS and KICA.<sup>1</sup> The benefits include:
  - The tools have been tested and have some veracity
    - According to research the best outcomes occur when traditional methods and mainstream practices are used together ([http://aams.org.au/mark\\_sheldon](http://aams.org.au/mark_sheldon))
  - They acknowledge cultural beliefs and are inclusive of spirituality
  - They involve the family
  - They build rapport with the community
  - They are often more flexible than other models
  - They highlight the need for early intervention
- Need to recognise that there are different cultural norms and patterns including amongst different Aboriginal communities. Need to be sure that specific behaviour, which may seem unusual to Western eyes, are generally mental illness related and not just socio-behavioural related. There is still far too much misdiagnosis of Indigenous people occurring
- Issues to consider when engaging with Aboriginal consumers include:

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<sup>1</sup> <http://www.indigenoupsychservices.com.au/viewStory/WASC-Y+%28aged+13-17%29> and <http://www.wacha.org.au/kica.html>

- The setting is important. Often traditional assessment spaces are not appropriate
  - Different styles of interview techniques. For example:
    - Avoid constant eye contact and lower one's gaze
    - Do not 'invade' personal space
    - Allow the participant to choose where and how the discussion takes place
  - Having the family and community involved is very important
  - Use of the term 'weak spirit' is often helpful
  
  - If no family present:
    - Try to track down someone, even if it means they have to travel
    - Think about other community relationships and community organisations
    - The local Aboriginal Medical Service could advise as well.
  - Building trust with the individual and their family and community is essential: where there is little or no trust there is no relationship and therefore no support and assistance can be provided.
- What should occur in the future is:
    - Development and dissemination of clinical guidelines for working with Aboriginal consumers
    - Ongoing cultural training of all mental health staff
    - More recruitment and training of Aboriginal staff who continue to work in the mental health field
    - Move towards a service system that is focused on prevention and away from crisis management
    - Consultation is important to building rapport, but too often in the past Aboriginal communities have seen no benefits from engaging in this process, so are wary of 'more talk and no action'
    - Do not be over sensitive when dealing with Aboriginal consumers. Trying to assist is far better than not when a problem or situation arises
    - Preferable to keep eyes down when wishing to engage with an Aboriginal person. It is respectful and non-confrontational.

## ▪ **Research Plenary (6.0)**

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*The goal of this workshop session was to discuss why consumer and carer participation in research is important. There were two presentations provided.*

*The first presenters (**Lei Ning** and **Rosemary Callander**) aimed to demystify research and provide a brief introduction to consumer and carer involvement in research.*

Key issues and actions arising from Lei and Rosemary's presentation and discussion included:

- There is now a widespread expectation that all policies and practices are evidence-based, meaning they are supported by sound research and demonstrated outcomes. This is as true for clinical services as it is for other forms of social research.
- While we might aspire to be neutral and scientific, we need to also acknowledge all research involves value judgements.
- There were three main models of participation research (after Beresford, 2007):
  - 1) Reference Group
  - 2) Collaboration Research
  - 3) Consumer/ Carer Initiated Research
- Characteristics of consumer/carer driven research is where consumers/ carers define:
  - Agenda
  - Values
  - Involvement
  - Process
  - Transparency
  - Dissemination (of findings and outcomes)
  - Change (that the research leads to).
- It was noted the Department of Human Services Victoria has funded a consumer/ carer research project involving 8 services as part of a pilot. The project involves consumers and carers defining the key research questions that will drive a quality improvement process in each service. The outcomes of this action planning process are not complete at this stage.

*The second presenter (**Kathy Griffith**) explained the importance of consumers participating in research and how it could be approached.*

Key issues and actions arising from her presentation based on the work in the Depression and Anxiety Consumer Research Unit (CRU) at the Australian National University included:

- There are a number of assumption that underpin consumer driven research:
  - Consumers are the experts
  - They possess a broader and different focus (to that of service providers)
  - Their views are more relevant and valid to the topic than many others
  - It is important to facilitate their input to research and disseminate the outcomes of the process
  - There needs to be an ethical and consumer-sensitive approach
  - There is value in undertaking this kind of research - What could be more important than really knowing what consumers want/ need/ experience?
  - Consumer research increases the accountability of the research (based on the combined effects of the above points).
- The advantages of consumer based research include:
  - Empowerment
  - Ownership
  - Voice
  - De-stigmatisation.

- An important threshold question is what are the right research questions to ask from a consumer's perspective
- Two techniques for acknowledging and respecting consumer involvement include:
  - Employing suitably qualified consumers as research assistants
  - Reimbursing expenses.

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## ▪ **Mental Illness: A Young Person's Illness (7.1)**

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*The goal of this workshop session was to discuss youth mental health and explore current issues and ways to improve service provision for young consumers across Australia.*

Key issues and actions arising from **Vittoria Tonin's** presentation and the discussion following included:

- The highest prevalence of mental illness is amongst young people, aged 15 to 25 years. They have what has been termed the 'greatest burden of disease'. Further, 75% of mental illness in Australia manifests by the age of 25.
- What Australia needs is a mental health system that specifically caters for young people and does not force these vulnerable individuals into unsuitable, adult services.
- Young people who acquire mental illness before 25 years do so at a very difficult phase of life. This includes:
  - Undergoing major developmental milestones and issues, including trying to establish a separate identity to parents and childhood peers
  - Exposure to alcohol and other drugs for the first time
  - Acquiring adult responsibilities and yet not necessarily skilled or confident to do so
  - Managing the pressures of school and peers
- When young people experience mental illness the most common feedback is they did not know where to go or who to turn to. Often their families and carers do not understand what they are going through or where to get help either
- The reasons for having youth mental health services are many, but include a recognition that:
  - Young people are different to children and adults
  - They have different help-seeking behaviours and can be easily put off by a sense that they do not belong or are not welcomed
  - If they do not receive early intervention, many young people end up with broken or disrupted education and employment histories that can make later stability very challenging.
- Based on the headspace model in Melbourne, one of the most successful types of mental health service for young people has the following features:
  - A primary health care model
  - Community based and specifically young person oriented
  - Aims at early intervention and crisis prevention and treating the individual before they are chronically unwell
  - Provides a continuum of youth appropriate services in a single location

- Issues for the future include:
    - Even though the Commonwealth Government funded an additional 20,000 youth mental health places through the headspace model, this still is not enough. Need to advocate for much more services for young people given the scale of problem
    - There needs to more consideration of Aboriginal and CALD specific services models and how existing services need to be changed to better cater for these groups of young people
    - Needs to more access to youth specific services in rural and regional parts of Australia.
  
  - **Participatory Action Research for Service Evaluation (7.2)**
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*The goal of this workshop session was to learn about the theories, principles and methodologies of Participatory Action Research (PAR) and how to apply it in the everyday world of consumer participation and service evaluation.*

Key issues and actions arising from **Jon Kroshel's** presentation and the discussion following included:

- Participatory Action Research (PAR) was started in the 1940s and has a number of benefits including :
  - It is democratic and uses non-coercive research methods
  - It places power back with the consumer
  - It is totally inclusive
  - It does not just change 'one thing here and one thing there'. When done properly:
    - It actually changes the culture of services and of staff, as well as consumer attitudes
    - Both parties better understand each other.
- PAR can be used by consumer consultants and advocates to actively examine current actions people think should occur to improve services. It also can be used to evaluate services
- Currently PAR is taking place in 57 countries around the world. In Australia it is most widely practiced in Victoria due to government funding some years ago
- While PAR can be used in high level policy discussions, it is most commonly applied locally and at a service level. This is also where consumers can most quickly see the results of their efforts
- The technique involves the researcher facilitating a group of people to come together. Issues to consider include:
  - Creating a common identity and purpose amongst group members
  - Working out what they wish to change or focus on
  - Valuing different perspectives
  - Recognising the researcher is in the role of a privileged guest (of the group) and their role is to bring tools into the group

- Establishing an equal exchange between individuals and the researcher:
    - Comments are provided by consumers; options are provided by the researcher (not vice versa)
    - The group comes up with the questions. Together members decide:
      - How the group will be convened and run
      - How the research design will run and which tools will be used
      - How the collaboration will operate.
  - Consumer input should be recognised and where possible paid for
  - How the researcher asks questions and introduces material is critical. Conversational style interviewing is preferable for example (using grounded theory):
    - *What would you like to say about the mental health system?*
    - *And is there anything else you'd like to say?*
  - The balance of people on groups is very important and it is important to not 'load it' against consumers or participants. One suggested configuration was:
    - 2 staff
    - 3 carers or family members
    - 5 consumers
  - Following the group process, the researchers synthesise the consumer comments and provide it back to the group, then they are provided to the service. The service then becomes the researchers and starts to work with consumers to respond
  - Consumer groups should not just be acknowledged; they actually need to be given full credit for the findings. They decide if the findings should be presented externally
  - PAR is by nature experimental; it increases the knowledge of all participants- the consumers, the researcher and the service.
- **Recovery Plenary (12.0)**
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*The goal of this workshop session was to allow participants to explore recovery from a number of perspectives. There were two presentations provided.*

*The first presenter (**Michael Burge**) provided an introduction and overview of wellness tools for how consumers and carers can take care of themselves. The presentation included a bound handout prepared by Michael.*

Key issues and actions arising from Michael's presentation and discussion included:

- There were many useful tools to help consumers and others manage their own recovery and wellbeing. Some well established models include:
  - Wellness Recovery Action Plan (WRAP)
  - My Action Plan (MAP) for family members and significant other adults.
- Sometimes just a simple check list can help people realise that they are at risk of sliding backwards
- Stress happens to all people but there are some things one can do about it, including things such as:

- Learn stress management strategies
- Ensure you get enough food and sleep
- Prioritise and realise you cannot do everything
- Maintaining realistic expectations, boundaries and beliefs
- Make decisions. Not making decisions causes stress
- Relax whenever you can
- Think positively
- Do not take criticism personally
- Have fun and learn to laugh at yourself
- Challenge unhelpful thinking.
- Learn to know what you are like when you are:
  - Feeling alright
  - Starting to feeling not so alright/ under stress.
- Also know, and have others who care about you know:
  - What your triggers are
  - What your early warning signs are
  - What your symptoms are when things are really starting to go awry
  - What happens when things are getting worse.
- Prepare lists and action plans of things you need to do to look after yourself:
  - Everyday to keep yourself feeling alright
  - To manage or avoid your triggers
  - To do when early warning signs are there and you or others have seen them
  - To help reduce symptoms when they have progressed to the getting worse point.
- Prepare and provide a copy to significant others, including main treatment staff, what people should do to assist you in different phases. This is especially true in terms of treatment options and medications
  - If there are things you definitely do not wish to happen, write it down, have it witnessed and agreed to by key staff and significant others when you are well, so that it can be called on when you are not.
- Nominate a support person or buddy who you trust will look out for you and advocate for your wishes when you might need their assistance. Be sure that key personnel know of these individuals and are aware they can be called on when a specific set of symptoms or situation arises.

*The second presenter (**Frederick Ford**) discussed recovery in the whole of community context, from the perspective of the carer.*

Key issues and actions arising from Frederick's discussion included:

- Up until recently, recovery has been seen as largely about the individual living with mental illness and their particular journey. This has meant that the whole of community context has been neglected
- If recovery is to be viewed as a social process that involves reconnecting with others and the world, then the positive contributions of supportive family members and carers must be focused on as well

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- For carers to be a positive influence on the people they care for three things are important:
    - Informed
    - Knowledgeable
    - Supportive.
  - Carers also go through a recovery process though clearly a different type of recovery to the person with mental illness
    - Often carers have an unrealistic expectation of recovery. They think it implies returning to where they and the person they care for was before
    - This is frequently not the case, though some of the old and valued ways of interacting can be restored
    - The important thing though is to not have expectations that this is what will occur.
  - From the carers' perspective the tools of recovery include:
    - Empathy-  
the ability to walk alongside the person we care for
    - Non-judgementality-  
acceptance for the way they are at the time and separating the illness from the person
    - Knowledge-  
about the illness and also knowledge of one's own stresses and issues
    - Quality communication-  
this not only relates to communication with the individual, but also with the providers in cooperation with the person with mental illness
    - Honesty and Respect-  
a capacity for the consumer to discuss things honestly with you, and you to also be able to discuss things honestly with them. This also includes a capacity to not agree and to respect and acknowledge that in an honest and constructive way
    - Setting appropriate boundaries or limitations-  
this includes knowing when to hand back to the consumer or wind back some of the activities previously needing to be performed. This is one of the hardest things to manage and one many carers find very difficult to do.
  - From a carer's perspective, recovery has many phases and repeats as well. This can include:
    - Grief and loss, including nostalgia for what we think was a 'normal life'
    - Blame and guilt
    - Loss of careers and interests
    - Change in life goals and roles
    - Taking on extra responsibility
    - Stigmatisation (including the negative responses of some friends and family members)
    - Social isolation
    - Continual changes in circumstances and expected roles. This might include the end of your role as a carer, or the end of a particular type of carer role and this needs to be prepared for.
  - One of the most important things a carer needs to do is self care: making time for self
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- If carers do not look after themselves there is a risk that carers will become burnt-out or even suffer their own mental illness issues. This needs to be prevented.
  - Ultimately carers and other community supporters need to be respected, supported and recognised for their roles. They need to work through their own healing and discovery about what recovery means for themselves and for their loved ones. This process is not easy but the more we talk and recognise it, the better the situation should become.
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- **Stigma and Discrimination (13.1)**
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*The goal of this workshop session was to discuss mental health promotion and illness prevention options to reduce mental health stigma in the community.*

*The presentation, by **Jeff Cheverton**, drew on the images and findings of a recent Churchill Fellowship research grant to travel to New Zealand, England and the United States to look at public media campaigns, including TV advertisements aimed at addressing stigma.*

Key issues and actions arising from Jeff's presentation and the discussion following included:

- Addressing stigma and discrimination is a complex issue and needs to focus on changing community attitudes
- There is a difference between mental health awareness raising and anti-discrimination and anti stigma campaigns. This difference changes how advertisements are presented
- Evidence suggests there are many benefits to public awareness raising campaigns including:
  - Improved understanding by members of the community
  - Improved attitudes to people with mental illness
  - Building bridges, creating empathy, and opening up opportunities
  - Cost saving by encouraging individuals to seek help earlier.
- Some key components of effective anti-stigma campaigns include:
  - A focus on social inclusion and portraying people with mental illness as ordinary members of the community, doing everyday activities. This serves to normalise mental illness
  - High quality images and production value. The reach and power of the mass media should not be underestimated
  - Campaigns should be led by people with a lived experience of mental illness BUT these individuals are not the key audience for most campaigns. This is the general public
    - Sometimes this raises a challenge in portrayal as there needs to be a balance in portraying the positive messages without glossing over the difficulties and challenges facing people living with mental illness.
  - Promoting positive images and hope and avoiding fear is a powerful message, especially when using real consumers and carers. The New Zealand campaigns were particularly effective in this respect
  - Focusing on ordinary people in ordinary settings provides a strong message of acceptance and anti-discrimination

- The most effective campaigns are ones that are not just mass media and advertisement based, but supported by a grass-roots program of linked activities aimed at direct contact and education. When most effective (as in New Zealand) these were:
    - Multifaceted
    - Multilayered
    - Focused on different regional centres (e.g. 26) and with specific cultural groups (e.g. 4 for Maoris and Pacific Islanders; 1 for Chinese based in Auckland in particular)
    - Run over a number of years.
  - There is value in just focusing on discrimination and not trying to also address prevention or help related issues. These should be the subject of other initiatives. i.e. you cannot do all things at the one time
    - Other complementary options include challenging stereotypes particularly in how the media reports stories.
  - To date there have been no campaigns in Australia to reduce stigma towards people with mental illness and it is well overdue. The best way forward would to initiate a broadly based campaign that runs over a number of years and includes local, community based activities, education programs, as well as public media advertisements
    - The Queensland Alliance has made this issue a top priority. Their website has a 60 page document on what was learnt from the overseas visit
    - Individuals should lobby their local members to support the MHCA application put forward for \$45 million over 3 years to run such a campaign
    - Some of the funding should be run through consumer and carer organisations to drive effective local initiatives
- **Employment Opportunities for Consumers and Carers (13.2)**
- 

*The goal of this workshop session was to discuss what future employment for consumers and carers could look like?*

Key issues and actions arising from **De Backman-Hoyle's** presentation and the discussion following included:

- Consumer and carer access to employment opportunities varies considerably between states and territories. There is also unevenness within states depending on where you live
- Currently workforce initiatives for consumers and carers have various negative perceptions and realities. They are often:
  - Tokenistic
  - Vague role definition and purpose
  - Lack of support
  - Without clear award structure and therefore remuneration levels are often questionable
  - Without supervision, and generally no peer supervision

- Characterised by poor communication and information flow. For example, employees do not receive agendas and minutes prior to meetings.
- Receiving little opportunity to up-skill and receive training
- Without career structure or advancement opportunities
- Placed in inappropriate situations or roles
- Given too broad a role, so can seem to be set up to fail
- Lacking recognition of skills, capacities and lived experience of consumers and carers which leads to a lack of respect.
- Other challenges are that some consumers do not have standing with other consumers. In some cases, they are even thought to be non-consumers and therefore should not be in these designated roles
- In order to strengthen employment opportunities in the future, the following options were discussed:
  - Provide better networking opportunities between consumers and carers, including between different states and territories
  - Use good practice models, promote greater recognition of the value and use of consumers and carers in the workforce and how it could be strengthened
  - Promote recommended pay and work conditions to assist employers to know good practice
  - Identify and promote useful training opportunities to assist consumers and carers to up-skill and be supported by other peers
  - Work in local contexts to clarify and document both appropriate and inappropriate roles and responsibilities
  - Establish processes and procedures for addressing situations when there has been poor communication or lack of respect for consumer and carer employees.

#### **4) HUMAN RIGHTS THEMES AND ACTIONS ARISING**

Across the two day National Register and NMHCCF Annual Workshop, a number of key themes and issues emerged that were found to be impacting on the human rights of mental health consumers and carers, including issues related to their quality of care, access to support, and opportunities. Some key themes and actions included:

- The Government's recent rejection of an Australian Bill of Rights in favour of a National Human Rights Framework. This was viewed as both a disappointment and an opportunity.
  - Participants were very keen for mental health issues to be included in the advertising campaigns, as well as funding allocated to staff education.
  - It was agreed that a communiqué be written by the workshop participants on the topic of mental health issues and the Human Rights Framework. The major agreed messages were that mental health issues needed to feature prominently in the:
    - Workforce education initiatives
    - Public awareness and media campaigns

- Participation and citizenry based inclusion initiatives.  
(See attachment B).
- The human rights of people with mental illness in Australia was noted as being challenged or violated in various ways including:
  - Prohibition against smoking in health facilities, especially for involuntary patients. Some participants advocated for the need to establish designated outdoor smoking areas in each facility, rather than provide only nicotine replacement therapy
    - It was noted that inpatients were usually very stressed and vulnerable, and as they were dealing with many other changes and treatment interventions, this was not conducive to quitting smoking
    - It was also noted that some jurisdictions are also looking to extend prohibitions on smoking to non-government providers in receipt of health funding
    - Participants noted that the rights of smokers need to balance with the rights of other consumers and staff. It was also noted that the issue tended to raise strong views on both sides of the argument.
  - The ongoing use of cramped refugee facilities and inadequate access to quality mental health care
  - The proposed changes in NSW to postpone the review of individuals compulsorily detained. Similarly in Western Australia this can apply for up to 8 weeks
  - Issues related to accessing various types of insurance for people with mental illness. It was noted that this could be the subject for both individual complaints to the Human Rights Commission, as well as some joint policy action on behalf of MHCA.
- Under the theme of human rights, participants generated a list of issues that required further advocacy and consideration. These included:
  - Forced treatment, and issues associated with seclusion and restraint
  - Rights of young people with mental illness and their lack of access to services
    - There were also issues to do with carer and family involvement and their right to know information about the young people they care for
    - The issue of separated parents and providers sharing feedback with both parents remains an ongoing challenge.
  - Children with mental illness, as this group is often not identified as experiencing mental illness and thus fall between the gaps
  - Various mental health access and supply issues, given the current inequities that exist in Australia based on where you live, your age, and if you have any special needs or cultural requirements
  - Lack of access to safe, appropriate and affordable housing especially when secure and sustainable accommodation is a known critical factor in recovery

- 
- Challenges facing clients with dual diagnosis and the need to frequently span two health systems that generally do not work well together
  - Social exclusion and discrimination experienced by people with mental health issues when accessing mainstream services including general health care
  - Discrimination in the media coverage of individuals with mental illness and the breach of privacy norms
  - Discrimination and stigmatisation in workforce participation, including issues arising from:
    - Changes to the Disability Support Pension
    - Economic exclusion.
  - Issues relating to delays in coronial inquiries into people with mental illness as justice delayed is justice denied.
  - Various regulation and legislation related to access to medical records and a consumer or carers right to know.
  - It was agreed that all of the above human rights and mental health issues could be actioned in various ways including via the Government's Human Rights Framework.
    - In this respect there could be separate or collaborative action by the MHCA, the NMHCCF and/or by the National Register
    - Some options discussed included:
      - Preparing and distributing common briefing notes that could be used in advocacy at all levels
      - Coordinating petitions on specific issues
      - Advocating in local networks and decision making arenas
      - Taking action through local members and elected officials.
  - One participant shared with the group a powerful quote that was widely supported:

*We as a society have managed to find ways to restore varying degrees of normality and dignity to the lives of people who are blind, paraplegic, or who have diabetes. We need to do the same with people with mental illness, particularly for those people with psychiatric disability.*

**5) OTHER ISSUES DISCUSSED AND ACTIONS ARISING**

- While mental health was currently receiving more public attention than at any previous time, it was noted that there was still need for strong advocacy and coordination of effort to improve outcomes for consumers and carers
  - It was noted that public advocacy works best when it operates simultaneously at various levels, including in particular at the local community level. This includes:
    - Gathering a number of like-minded consumers or carers and seeing one's local member of parliament. This can do a lot to ensure there is understanding of the issues affecting consumers and carers.
- The workshop acknowledged the contributions and efforts of past and present consumers and carers whose individual and collective efforts had made the mental health system better for others
  - These individuals, while possessing a vast depth of lived experience and knowledge of the mental health system, mostly worked in their own time, without remuneration, at times at a cost to their own health, and with impacts on their families and friends
  - Frequently their efforts went without sufficient recognition and were often under valued by decision makers and those within the health system
  - It was noted that many felt isolated and needed support, but that that if they did not continue in their advocacy, others would suffer
  - To improve this situation it was noted that:
    - The efforts of consumers and carers needed to be more broadly recognised and valued
    - An expanded and better connected network of skilled advocates who could share the load could assist
    - There needed to more awareness of the importance of 'self-care' to ensure individuals do not burn-out and have ways to self-monitor so their own health and wellbeing are not jeopardised
    - Stronger networks and support structures need to be established at different levels to assist individuals to remain effective and healthy in their roles.
  - There was also a need for younger representatives and those representing cultural and linguistically diverse backgrounds and those with Aboriginal and Torres Strait Islander heritage.
- In addition, participants at the workshop discussed the strength and support they drew from meeting with each other and sharing in both formal and informal settings their personal experiences of the mental health service system across Australia. As the attached evaluation summary testifies (see Section 6), participants highly rated the benefits of coming together from all states and territories and being able to learn new

policies, practices and skills relevant to their mental health support and advocacy roles. They noted the need for there to be more opportunities for this to occur in the future, including through forums such as the National Register/NMHCCF Annual Workshop.

## **6) EVALUATION OUTCOMES**

Participants at the National Register/NMHCCF Annual Workshop were invited to provide feedback on each of the workshop sessions, as well as an assessment on the workshop as a whole. The overall feedback was very positive with 97% of participant respondents (n=38) reporting the workshop a success; 91% reported their understanding of human rights in a mental health context had improved as a result of the workshop.

Over 80% of respondents also reported the 2010 Workshop had improved their:

- knowledge of current national mental health consumer/ carer issues (94%)
- knowledge of different responses to consumer/ carer issues across Australia (97%)
- capacity to be an effective consumer/ carer representatives (88%)
- ability to lobby or advocate for consumer/ carer issues (82%)
- confidence in discussing mental health consumer/ carer issues (82%).

In addition, 97% of workshop participants reported the workshop was either successful or very successful in promoting networking opportunities between participants.

When participants were asked what they found most valuable in terms of their participation in the workshop, the majority indicated the networking opportunities and the opportunities to learn from, and be supported by, peers in other states and territories.

Participants highly rated the two keynote presentations (*see Section 2*). All respondents indicated both Graeme Innes and Patrick McGorry contributions as informative, of practical use to the participant's role, and interesting.

The two plenary sessions, the first focused on Research and the second on Recovery (*see Section 3*), were also appreciated by participants with many commenting on the value of having more than one presenter and perspective provided.

Similarly, those who attended the various break-out sessions (*see Section 3*) found them generally very informative and of practical use, with numerous individuals commenting on the value of the group discussion following the presentations.

In terms of how the workshop could have been improved, or what might be included in future workshops, a broad range of constructive ideas were provided including:

- more guest speakers, expert in areas of interest to the sector
- opportunities for more practical skills development (including effective lobbying)
- opportunities to discuss strengths and improvements in the mental health system (and not just problems and challenges)
- scheduling keynote speakers before the end of Day 2 to better cater for those forced to catch earlier flights.

Suggestions for future workshop activities included:

- inclusion of Commonwealth Government speaker
- possible sessions on:
  - managing conflict
  - dual diagnosis
  - ethics
- more skills based workshops and consumer/ carer driven presentations

It was also suggested that the theme of working with culturally and linguistically diverse consumers and carers would be a good subject for a future plenary session.

In general, participants indicated the 2010 Workshop was an improvement on the previous year, and that they looked forward to the hosting of another National Register/NMHCCF Annual Workshop in 2011.

## **7) FURTHER INFORMATION**

For further information on the National Register or NMHCCF of mental health consumer and carer representatives or for copies of presentations delivered at the 2010 Workshop please contact:

Kim Harris  
Administration/Project Officer  
Mental Health Council of Australia

Tel: 02 6285 3100

Fax: 02 6285 2166

Email: [kim.harris@mhca.org.au](mailto:kim.harris@mhca.org.au)

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## ATTACHMENT A

**NATIONAL REGISTER OF MENTAL HEALTH CONSUMER AND CARER  
REPRESENTATIVES**

**2010 WORKSHOP PROGRAM**

**29 – 30 April 2010, Holiday Inn Melbourne Airport**

**DAY ONE - THURSDAY 29 APRIL 2010**

TIME	SESSION	
9.30	1.0 Registration	Holiday Inn Melbourne Airport Tea and coffee available upon arrival
10.00 – 10.15	2.0 Welcome	David Crosbie – CEO, MHCA To include recognition of consumers and carers past – Darren Jiggins and Lynette Pearce
10.15– 10.45	3.0 Scene setting presentations	<b><i>Theme of Rights</i></b> Goal: Provide a voice for mental health consumer and carers in National human rights debate <b><i>Presenter 1-</i></b> Tony Fowke <b><i>Presenter 2-</i></b> Desley Casey CAN (Mental Health) Inc. Does the smoking Ban in health facilities co-exist with the UN Convention on the Rights of People with Disabilities
10:45 – 11.30	4.0 Facilitated Q&A Session	Goal: A chance for consumers and carers to reflect on the previous session and share their views. Participation from the floor will be encouraged, with the facilitator aiming to draw on the diverse interests, backgrounds and experience of the group.

11.30 – 12.30	5.0 BREAKOUT SESSIONS:	
	5.1 Systemic Advocacy (or how to change the mental health system)	<p>Session Goal: Participants will explore systemic advocacy – What is it? How is it used? Who can use it?</p> <p><b>Moderator:</b> David Lovegrove</p> <p><b>Presenter:</b> Patrick Hardwick</p>
	5.2 Cultural Issues in Mental Health	<p>Session Goal: This session will enable participant What's the problem? Access or Service Delivery?</p> <p><b>Moderator:</b> Ingrid Bentsen</p> <p><b>Presenter:</b> Brendan Church Chief Executive Officer Aboriginal Justice Centre</p>
12.30 – 1.30	<p>LUNCH – VARGAS restaurant</p> <p>WORKING LUNCH - (networking by states, VIC/TAS/QLD/WA)</p>	
1.30 – 2.30	6.0 Research plenary session:	<p>Session Goal: Why consumer and carer participation in research is important?</p> <p><b>Presenter 1</b></p> <p>Lei Ning and Rosemary Callander</p> <p>Demystifying Research - A brief introduction to consumer and carer involvement in research</p> <p><b>Presenter 2</b></p> <p>Professor Kathy Griffith</p> <p>Director of the Depression &amp; Anxiety Consumer Research Unit, Australian National University.</p>

2.30 – 3.30	7.0 BREAKOUT SESSIONS:	
	7.1 Mental illness: A young person's illness	<p>Session Goal: Participants will discuss youth mental health, exploring current issues and ways to improve youth mental health services in Australia.</p> <p><b>Moderator:</b> Lynette Pearce <b>Presenter:</b> Vittoria Tonin</p>
	7.2 Participatory Action Research (PAR) for Service Evaluation	<p>Session Goal: Participants will learn about the theories, principles and methodologies of Participatory Action Research (PAR), and how to apply it in the everyday world of consumer participation and service evaluation.</p> <p><b>Moderator:</b> Judy Bentley <b>Presenter:</b> Jon Kroschel</p>
3.30 – 3.45	AFTERNOON TEA	
3.45– 4.45	8.0 Guest Speaker	<p>Graeme Innes AM, Disability Discrimination Commissioner</p> <p>“Rights”- A practical discussion of your rights under the Disability Discrimination Act and DisCo (Convention on the Rights of Persons with a Disability)</p>
4.45	9.0 Closing Remarks	Edwina Deakin – Facilitator
5.00	Day 1 Close	
6.30 for 7.00	Dinner	Holiday Inn, Melbourne airport

**DAY TWO – FRIDAY 30 APRIL 2010**

TIME	SESSIONS	
9.00 – 9.15	10.0 Facilitated Feedback Session:	A chance for participants to provide their views on the previous day's activities and what they hope to achieve from Day 2.  Facilitated by Edwina Deakin
9.15-9.30	11.0 Opening Speaker	Mr Tony Fowke President, World Federation of Mental Health  The World Federation for Mental Health – Is it relevant?
9.30 – 10.30	12.0 Recovery Plenary Session:	Session Goal: Participants will be given a chance to explore recovery, considering the value of using effective wellness tools (Presentation 1) and the family/ carer perspective (Presentation 2).  <b>Presenter 1-</b> Michael Burge Introduction and Overview of Wellness Tools for taking care of ourselves  <b>Presenter 2-</b> Fredrick Ford Recovery in the whole of community context
<b>10.30 – 11.00</b>		<b>MORNING TEA</b>

11.00 – 12.00	13.0	BREAKOUT SESSIONS:	
	13.1	Stigma & Discrimination	<p>Session Goal: Participants will have an opportunity to discuss mental health promotion and illness prevention options to reduce mental illness stigma in the community</p> <p><b>Moderator:</b> Lyn English</p> <p><b>Presenter:</b> Jeff Cheverton CEO, Queensland Alliance of Mental Illness and Psychiatric Disabilities Groups Inc</p>
	13.2	Employment Opportunities for consumers and carers	<p>Session Goal: What could future employment for consumers and carers look like?</p> <p><b>Moderator:</b> Noel Muller</p> <p><b>Presenter:</b> De Backman-Hoyle</p>
12.00 – 1.00		LUNCH- Vargas Restaurant WORKING LUNCH - (networking by states, ACT/NSW/NT/SA)	
1.00-2.15	14.0	Small Group Discussion	<p>Session Goal: Will reflect on key issues and learnings from the past two days, and future directions for consumer and carer leadership in Australia</p>
2.15 – 2.45		AFTERNOON TEA	
2.45-3.00	15.0	Closing Remarks	Edwina Deakin – Facilitator
3.00 – 4.00	16.0	Closing Speaker	<p>Professor Patrick McGorry <b>Australian of the Year</b>, Professor of Youth Mental Health at the University of Melbourne</p> <p>Clinical Director of ORYGEN Youth Health Executive Director of the ORYGEN Research Centre</p>
4.00		WORKSHOP CLOSE	

**ATTACHMENT B***Communiqué from National Mental Health Consumer Carer Register Workshop****NATIONAL MENTAL HEALTH CONSUMER AND CARER LEADERS CALL FOR ACTION UNDER THE GOVERNMENT'S HUMAN RIGHTS AGENDA***

Discrimination and a failure to provide basic human rights is a major priority and election issue for members of the National Register of Mental Health Consumers and Carers and the National Mental Health Consumer and Carer Forum.

At a workshop held in April 2010, 46 individuals representing mental health consumers and carers from across Australia agreed that discrimination and improving the human rights of people affected by mental illness must be addressed by all tiers of government and that the failure to provide basic human rights must be urgently addressed, especially during the forthcoming federal election.

The representatives, who attended a workshop in Melbourne for the National Register of Mental Health Consumers and Carers and the National Mental Health Consumer and Carer Forum, called for the rights of people with mental illness to form a major component of the Australian Government's Human Rights Framework.

"Australians affected by mental illness experience discrimination on a daily basis. People with mental illness and their carers are often denied their fundamental human rights," said Tony Fowke, Workshop Participant, President of the World Federation for Mental Health and a spokesperson for the group.

"Discrimination begins with a lack of access to the types of health and community support services needed by mental health consumers to be treated equally in society. This is also evident in the way they are treated when they try to gain employment or insurance coverage, not to mention how people with mental illness are often referred to in the media."

"We call on the Australian Government to ensure that funding allocated under its Human Rights Framework includes a major focus on the issues affecting people with mental illness".

These leading mental health consumer and carer representatives strongly believe mental health issues should feature prominently in school and staff education programs, in community engagement and public awareness campaigns, and in participation strategies including policies and statements about human rights.

*For further information, contact Mental Health Council of Australia:*

Mr Simon Tatz – 02 62853100 or 0402 613 745

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