

**Inaugural meeting of the Council of Non-government Organisations (CONGO)
Canberra
Tuesday 09 October 2012
Extract of Panel Session
Presented by
Michael Burge**

I was recently asked to address the CONGO as a consumer representative and as the Consumer Co-Chair of the National Mental Health Consumer & Carer Forum (NMHCCF) and provide brief comments re the significant fragmentation issues across mental health and allied services that are affecting the continuum of care available to people using those services. The panel session was facilitated by Sophie Scott (ABC National Medical Reporter).

I wish to make it quite clear that I am not representing QHealth here today – I am here as an independent Mental Health Advocate and Consumer Co-Chair of the National Mental Health Consumer & Carer Forum (NMHCCF).

Firstly I wish to let you know where I am coming from – for almost 17 years as a consumer advocate (6 part time with Veterans Affairs & the last 11 full time as a Mental Health Advocate). During this time I have been listening daily to grass root consumers who utilise both public and NGO MHS's and I have had the privilege and honour to share many heart felt moments. I have also represented consumers on various State & National Committees.

My primary role is to promote consumer & carer participation in every aspect of care and/or treatment.

How many organisations here today came along with a consumer to ensure that had a chance to have a say – I'm not just talking about bringing a token consumer – but a consumer who has been adequately briefed and understands the complex issues behind Partners in Recovery.

As the singing group Aerosmith said in his song “I don't wanna miss a thing” therefore I will use my notes today.

I want to make it clear right up front that I think that “Partners in Recovery” is the best initiative for many years & I also believe in effective coordinated care – but in reality consumers just don't see the existence of this across Australia within a system based on Crisis Intervention and Hospitalisation.

Unfortunately there is also an underlying presumption that we have effective coordinated care between organisations (public & private). Services might believe they have coordinated care but the individual is not party to this & are usually the last to find out that their care is coordinated.

Back to the question of - how this is experienced by mental health consumers and carers?

It can make the consumer feel hopeless, frustrated, and disconnected from the very services who are supposed to be aiding in their recovery. It can also make them feel disconnected from themselves, friends, families and the community. Consumers just want the same treatment & care that everyone else expects and receives.

IT'S JUST NOT GOOD ENOUGH ANYMORE – many consumers say what continuity of care – it feels like a lucky dip from one location to the next – you never know what to expect.

Many services don't understand &/or address the diverse & complex needs of clients largely due to the narrow focus they have in their own organisation.

For far too long the disadvantaged & marginalised are being let down by traditional service delivery models.

The reality and/or existence of coordinated care is often seen as farcical for those consumers who don't fit the "Socially Acceptable Model" For example: If you don't have a pleasant social front, and you are seen as difficult, the homeless, unemployed, people living in poverty, the people in the back lanes, the disconnected, socially excluded, people with addictions, the disadvantaged and marginalised, & believe it or not people recovering from a traumatic experiences in organisations and mental health services.

Why are services continuing to put the ambulances at the bottom of the cliff instead of at the top of the cliff?

- What happened to prevention & promotion?
- Why are services still creating barriers to access their services – I'm talking about the criteria that excludes many from getting the help they so desperately need.
- Where is the coordinated care when people really need it – it is often too little too late.
- This is not just about the worried well.
- It's not just a medical model world we live in.

Consumers wouldn't be falling through the gaps if we had a "No Wrong Door Approach".

I could give you many examples of this occurring but – I don't have time for that today. Here is just one story amongst many:

I know of a young lady who suffered from Depression, Anxiety and low self esteem.

She didn't know where to get help so she decided to self medicate using alcohol then she started using drugs.

She ended up mixing with the wrong company in order to get more drugs to self medication.

Her parents were very well connected and tried so hard to get her effective coordinated care through the local MHS – this didn't happen.

Unfortunately she ended up in Jail and when she was released got a job in a government department and soon after lost her job because of her past record.

This made her become unwell yet again & the cycle re

Where is the coordinated care when people really need it, it often too little too late.

This is a typical story of how the system fails someone.

If you or I was to get unwell where would we get coordinated care?

- Does everyone here know?
- Who is getting access?
- Where is it available?
- What are our choices?
- Why are people missing out?

How would you feel if - you had not one but a number of care plans from different agencies working independently with different goals, differing priorities, different agendas, different outcomes, competitive funding priorities, not sharing information with each other, not communicating with each other, not inviting each other to collaborative meetings about the person, no clear accountability, and worst of all not inviting the person themselves to meetings about them.

“Nothing about us without us”

How would you feel if - you continually had your treating doctor, clinician, type of treatment, place of treatment, care plan, recovery plan, and your medication changed numerous times throughout your care and treatment?

Are traditional services guilty of managing and maintaining a disability as opposed to assisting someone in their journey of recovery?

Consumers need to be moving through services and not get stuck there for years. If they are stuck then services need to ask themselves - what can we do differently to help that person in their recovery journey.

Services need to be saying
You can do it
We can help

I strongly recommend that all services look on the website and read the guidelines for Partners in Recovery and I also recommend you read the following two documents:

“Unravelling Psychosocial Disability”
published by
NMHCCF

“Taking our Place”
released by
Community Mental Health Australia (CMHA)

What is the answer - there isn't a silver bullet to any of this, this is a societal, government, whole of community issue that needs everyone coming together and being courageous, facing the uncomfortable and talking working together, not in competition but united.

We need leaders without egos – we must have a team of leaders who want to achieve a goal and don't care who gets the glory. This is not about services this is about meeting the needs of consumers.

Organisations need to put their past grievances you have with each other behind you and work together in true partnership & if you cannot then may 'be you should reconsider whether you are going to be an effective partner – you may be a hindrance to Partners in Recovery.

Services need to be truly collaborative in order to meet the consumer's needs and not just the organisations needs.

How many organisations here can truly say that they genuinely and meaningfully included consumers/participants in discussions about what is required to provide holistic, person centred care?

How many organisations here today came along with a consumer to ensure that had a chance to have a say – I'm not just talking about bringing a token consumer – but a consumer who understands the complex issues behind Partners in Recovery.

Nothing about us without us

How many organisations decided on who should be a collaborative partner without consultation with consumers and how many organisations still think they know more about what's best for the person in recovery than the person themselves.

Real Reform means changing not just what we call things but what we do - relabelling the current community case management practices and calling it Partners in Recovery will not see anything change

"A wombat dressed in different clothes is still a wombat"

The priority for all organisations must be Patient Centred & Directed Care which focuses on the things that people need to help their recovery.

- This must be about consumer choices not service provider options.
- We need better models of care through formation of effective Consortiums & Alliances that provide holistic care.
- Organisations need to be involved in consortiums for the right reasons – it should not be about money, ego's or glory.
- Organisations need to better understand and address the complex needs of the client and not just focus on the narrow interests of their own organisation.
- They must have people in their organisations & consortiums that can offer a diverse range of assistance – not just the traditional services.
Eg: Non-clinical (could be whatever), Housing, Centre-link, Family Services, Transport, etc ...or it could be as simple as buying the person a pair of shoes and or clothes if that is what they need.
- Organisations need to genuinely and meaningfully include consumers/participants in discussions about what is required to provide holistic, person centred care & not make those decisions for them.
- You cannot expect to have just one program that addresses the complex needs of consumers.
- We need to face the uncomfortable; by talking, working together, not in competition but united.
- We need a strong commitment towards having a NO WRONG DOOR APPROACH – we need to break down the barriers that currently exist in accessing services.
- What you provide must be measurable
 - Shared measurement is essential
 - Need a common set of measures to monitor performance, track progress towards goals and learn what is or is not working.
- Organisations must be accountable to the consumer.

We may need a steering committee which consists of a cross-sector of key partners – INCLUDING EXPERIENCED CONSUMERS AND CARERS.

Obviously we need a Backbone organisation that serves essential functions:

- That is capable of providing overall Strategic Direction, Facilitating Dialogue between Partners, Managing Data Collection & Analysis, Handling Communications, Coordinating Community Outreach, & Mobilizing Funding.

Ask yourselves this question:

Will the type of service you have and/or are developing help someone have a contributing life or will it hinder them?

Ask yourselves what makes consumers thrive and NOT just survive.

- Something meaningful to do and look forward to.
- NOT being stuck in the same service for years and years.

I will repeat this because this is so important:

These consortiums need leaders without egos – we must have a team of leaders within the consortium who want to achieve a common goal and don't care who gets the glory.

- Organisations need to be involved in consortiums for the right reasons – it should not be just about money.
- Partners must be able to form and sustain relationships.
- A genuine and meaningful relationship between partners is essential.
- Don't make this about the needs of services this is about the needs of the consumer/participant.

I was asked a question re what is value for money.

Value for money = it meets the needs of the consumer & it helps them have a contributing life – then its value for money.
e.g: Job, Home, Relationships, Socially Connected etc

Remember - Nothing about us without us

In finishing I want to end how I do with most of my presentations:

*People with a lived experience of mental illness may forget exactly what you said
They may even forget exactly what you did
But they will never ever ever forget how you made them feel*

Michael Burge IIMHL Ottawa 2007

Thank-you

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