



**Queensland Voice
for Mental Health Inc.**

**Consumer and Carer Consultation
for
Queensland Mental Health Commission**

December 2013



Queensland Voice for Mental Health Inc.

February 2014

Executive Summary

Queensland Voice for Mental Health welcomes the opportunity to assist the consultation process to contribute to the whole of Government planning by the Queensland Mental Health Commission.

Queensland Voice for Mental Health is the peak representative body for Consumers and Carers of Mental Health services in Queensland. We are an alliance of people with a lived experience of mental illness and our aims include:

- encourage, educate, and support our members in participation in health service planning, delivery, monitoring, and evaluation processes;
- promote, through advocacy, the needs, and goals of consumers, families and carers who access mental health, alcohol or other drug services, and including CALD and ATSI communities, throughout Queensland;
- advise Government and Non-Government Organisations on best practice for consumer and carer participation, engagement and;
- promote a holistic approach to recovery for individuals and their families.

As a voice for mental health, we seek to work for change, for the empowerment, recovery, and wellbeing of all and to promote a mentally healthy community.

In undertaking this consultation, which was funded by the Queensland Mental Health Commission, Queensland Voice undertook a community forum; gathered views by phone interview from members; and received mail and email feedback from a number of individuals and organisations. These consultations were specifically with consumers and carers regarding the questions agreed with the Commission.

The questions were:

1: Who, and how, do consumers carers and families see as representing their interests in the development of a Whole of Government Plan?

2: How should those representatives develop and maintain two way communications with “grass roots” consumers and carers throughout the State?

3: What do consumers and carers see as a “better system” (of mental health services) and how do we get there?

4: Who represents the lived experience paid and volunteer workforce that is so important to the sector?

This report summarizes the responses of the consumer and carers attending or interviewed. Notes from the consultation session, as well as a number of de-identified comments and suggestions that were provided during our consultations, these are included as an attachment. Also attached is an extract from Queensland Voice’s submission to the Establishment of a Qld. Mental Health Commission.

1: Who, and how, do consumers carers and families see as representing their interests in the development of a Whole of Government Plan?

Discussion was initiated with participants evaluating existing organisations and their role in providing consumer and carer representation, given that the statewide Consumer, Carer and Family co-ordination role inside Queensland Health was abolished during the restructure of the Mental Health Directorate.

Who should be responsible for the recruitment, co-ordination and support of consumer and carer representatives? There was some discussion relating to the differences and separation of consumer and carer interests and roles; and while it was recognised that there would always be different perspectives, and occasional conflict between the roles, it was largely agreed that the best results could be achieved when consumer and carer representatives work together.

The Queensland Voice model of a joint “Voice” rather than separate organization was accepted as having significant advantages. The separation of representation and advocacy from service delivery organisations was also seen as important with a degree of (probably unfounded) scepticism expressed about the risk for those organisations to become less responsive to the individual.

The establishment of the Queensland Mental Health Commission was seen as a particularly important mechanism for ensuring the voice of the “users” of the system are heard. A common complaint has been that “the system” does not listen. It was also considered important that those selected to represent consumers and carers on the Advisory Board had lived experience and were not only involved in clinical or service delivery functions.

Are we all here? Discussion covered the need to provide representation for a wide spectrum of consumer needs. This included not only the usual spectrum of location, age, gender, ethnic or social background differences but also the widely divergent needs of varying types of mental illness and, in particular, the ways in which those with more severe psychotic disabilities represent a high need, more challenging representation situation.

It is seen as critical that whoever represents consumers and carers has an understanding of rights legislation and the advocacy process. There are many situations within the Mental Health system, which involve limitations on the rights of the consumer. There is significant tension in the application of the wavering of those rights and it is important that anyone representing consumers and carers is familiar with, and takes into account the opinions of those being represented on such limitations.

Summary: *Consumer and carer representation has a chequered history with the perception among long-term users being that it has varied, and still does, from enthusiastic engagement to a token presence. In many cases, and despite the best intentions, user representation has been under-supported, undervalued, and frequently marginalized. Changing that perception requires careful representative selection and the provision of a support mechanism to enable them to carry out their function.*



2: How should those representatives develop and maintain two way communications with “grass roots” consumers and carers throughout the State?

A particular concern was that representatives need to communicate with, and be trusted by, those that they are representing and do not become “just another part of the system”. How do we spread representation so it is not just the same people involved all the time?

Gathering of views and information could be by interview or on line surveys. A particular concern was that such surveys be carried out by people with “lived experience” rather than as part of the clinical program. It was seen as particularly important that such surveys be carried out in a thorough and empathetic manner. Peer support workers were seen as a particularly important link for the dissemination and gathering of information, opinions, suggestions and criticisms of the system. There was praise for the Qld Voice newsletter and website acting as a clearinghouse for information, but it is currently only one-way communication. Further development of the QV website into a more interactive situation, using Facebook, YouTube or other technology, together with on-line surveys may assist but is beyond the current resources of that organisation. It was also noted that there are significant financial, technical or knowledge barriers to many consumers accessing the internet.

Comment was made that while communication through Psychiatrists, GPs and Caseworkers is useful, the area that seemed most respected and commonly used is the Pharmacist and that they should be developed as a communications link.

Payment and support for consumer/carer representatives on consultations was looked on as important to ensure that they were motivated and resourced to carry out their task. Currently the Government view of ‘support’ is very narrow e.g. taxi voucher, \$25 to attend a meeting and should be broadened by providing support training such as PeerZone.

Summary: By way of direct quotes from the forum on the ideal situation;

“These representatives have developed and maintained an involvement in Regional Mental Health and have shown a capability and interest in contributing to helping the system to improve and be better. They are involved in Government, non for profit organisations, service providers and individuals with a lived experience. They would attend monthly meetings in their region, and all regions need to have regular up-to-date ways of communicating information to the wider community, be it through newsletters (hospitals and other), local papers, social media, internet and radio”.

“Who - People with a ‘lived experience. How – In a regular and consultative manner with the Queensland Mental Health Commissioner on a bi-monthly basis. These representatives with a ‘lived experience’ are drawn from every region across Queensland”.

3: What do consumers and carers see as a “better system” (of mental health services) and how do we get there?

This question recorded the most significant level of response. The need for reform, innovation and improvement was expressed by all participants.

The most important need seen was for services to work complementarily with each other - currently they seem to work in competition or in separate “silos” with little or no communication within services let alone between sectors. This means that every engagement becomes a “start from scratch” encounter for the consumer or carer. The impediments to information exchange between clinicians, consumers and carers, and thence with other support services has left a system which is hamstrung and prevents the development of an engagement strategy to empower and inform.

The development of a significant Peer Workforce is seen as perhaps the most important step in making the system user friendly. It seems to be happening in a limited way but peer workers need mentoring and supervision on how to stick with it, avoid burn out, and cope with power plays and politics within health. They are a group with unique talents, but with their own needs.

There is seen to be a significant need for expanded therapy options such as CBT – talking therapies, nutrient power therapy – bio-chemists. All have a significant evidence base but appear to be ignored, particularly in the public system, in favour of a concentration of drug based therapy. Many consumers and carers consider that this is because the system is still focused on management rather than recovery.

Transparency and accountability needs to be significantly improved. Most consumers and carers complain that it is extremely difficult to gain a response to a question or complaint and that the “privacy and professional confidence” functions are frequently used to avoid responsibility. There are also gaps in the advocacy available in challenging clinical decision-making, and in the application of both criminal and civil law, which may flow from a diagnosis or medical opinion. Some sort of Ombudsman type service should be available.

There is a critical need to eliminate system gaps. A huge degree of waste and unneeded duress within the system are caused by the lack of dedicated and legislated pathways between different sections of the Public system, and the pathways between the public system and the private and NGO sectors. The *‘slipped between the cracks’* syndrome is more the norm than the exception.

There is a need for a road map of what paths are available, an overview of ‘the system’ that guides a user through the pharmacy/GP’s/hospital/support groups/ CAGs/NGO/peak bodies maze. It might be useful to have something like a *‘You are here’* map that provides the consumer or carer who is new to the system some insight into the services and responsibilities of each participant. Even better would be to have personnel at critical interchange points within the system, who are able to provide guidance and advice regarding the *‘next step’* and the options available.

Summary: *The best possible summary of a better system is a direct quote from a participant;*

“A ‘better system’ is always about listening, respecting and talking with the person/s with the ‘lived experience’. Working and walking alongside the person/s with the lived experience, for as long as it takes to enable the person to be confident to do or be for themselves; recognising the uniqueness and opinions of those with a lived experience; being open to different ways of treatment, have open dialogue and transparency in all dealings”.

4: Who represents the lived experience paid and volunteer workforce that is so important to the sector?

The forum and the membership of Queensland Voice place considerable importance on the development and training of a peer workforce. This is seen in the broadest possible engagement of people with a 'lived experience' as consumers or carers. The restructure of the Department of Health and the move to decentralized decision making through HHS administration and governance has superseded the previous arrangements for supervision and support for peer workers.

In certain areas, it has also lead to downgrading of their working hours and conditions and the withdrawal of other support functions. In particular, it has caused a reluctance to speak out among some peer workers in the public health system. Peer workers are often seen as an "easy target" for economy or cost saving moves because their role is not clearly defined by management and they do not have a representative body to protect their interests.

A statement was made that there are now only 19.5 consumer/carer consultant workers throughout Queensland Health down from 44 a few years ago. There are 87 Consumer companions throughout the state. This workforce was supported through the directorate – the Consumer Carer and Family Team has since been disbanded. There is a need for proper reflective supervision for these workers. There also was a yearly forum and monthly meetings, which provided opportunities for discussion and reflection.

Peer workers - a lot of consumer workers in the hospital system also have strong connections in the NGO sector or community groups. Peer workers in the NGO sector have similar issues to those in Queensland Health and could have same representative group. There is growth in the Peer worker workforce in the private and NGO sectors; and TAFE programs to formalize and improve training are under development or are being rolled out.

While there are small steps being made to regenerate supervision and information interchange between members of this critical workforce there is no formal organization with the resources in a position to guide and co-ordinate these activities.

Queensland Voice has acted as a sort of de-facto representative group but does not have the resources to carry out the task effectively.

***Summary:** There is a strong evidence base that a "lived experience" workforce is an effective integral part of the best mental health systems. This is particularly so if the system is focused on recovery. The Commission should look at encouraging and supporting that workforce by assisting in the development of representation and of guidelines for training, supervision and employment condition specific to those workers. The workers themselves need to form, or join an organization that will advocate for their rights and wellbeing.*

Attachment A

Extracts from the earlier forums regarding formation of the QMHC

The Commission should be:

- Acting as a strong advocate for mental health clients and their families;
- Improving the coordination, effectiveness and performance of mental health services;
- Ensuring resources are being deployed to where they are most needed;
- Developing a strong evidence base to support government investment;
- Promoting greater transparency in the allocation of resources.

Discussion

Ensuring the rights of consumers inform the basis of all policy and service delivery

A recognition and protection of the rights of all consumers and carers must underpin the operations of the Commission. This should cover a wide range of areas including treatment and care of people with mental illness, including the special needs of individual groups, social inclusion, accommodation, education, employment, early intervention, and prevention, and any necessary reform to mental health and related legislation.

The Commission should examine the administration and effectiveness of the legal provisions of the Mental Health Act, or equivalent, in relation to the rights of consumers, the prospects for recovery and welfare of persons under Involuntary Treatment Orders, Forensic Orders or in custody, with particular emphasis on whether risk minimization is removing the right to effective recovery based treatment.

Acting as a strong advocate for mental health clients and their families

The Commission must also focus on achieving strong and effective consumer and carer representation and participation mechanisms mindful of the following two factors:

- (a) Motivation and recruitment: - This requires a change in culture to ensure that from the earliest possible time all consumers, carers and families are made aware that they are part of, and contribute to, the ongoing planning, control and delivery of the services they are receiving.
- (b) Training and Support: - The provision of both, to achieve the skills to work as representatives, participating in the development of policy, planning, and governance.

1. Who, and how, do consumers carers and families see as representing their interest in the development of a Whole of Government Plan?

- Qld Carers – not so much mental health carers – more focussed on aged and disability carers.
- Queensland Alliance used to be a focal point.
- ARAFMI more particularly a service delivery – definite carer focus.
- **M F** of Health Consumers Qld said they see Qld Voice as the peak in the area of mental health
- Suggestion that Qld Voice as a focal point.
- Queensland Voice for Mental Health - the choice of the word Voice singular was deliberate to speak as one voice.
- **J**: It can be useful to have separate representation of carers and consumers – that carer voices can dominate. Mechanism needs to be in place so that this doesn't occur. This was carefully considered in formation of Qld Voice.
- Qld Voice has the right ethos but would need to be resourced and would need development.
- Pulling together of consumers and carers rather than separate groups.
- Representing diverse populations including young, old, rural, multicultural, regional, and indigenous starting out/near finish line of recovery journey. Comments seem to be same people at these consultations. Are we all here?
- Reflecting the diversity such as if 60% young people in population then 60% need to be on committee.
- **K**: I do not see there is any group representing the interests of those who suffer severe schizophrenia. I think the reason for this is because those who suffer severe schizophrenia are unable to organise to the same extent as those who suffer less severe mental illnesses. Generally, people who suffer severe schizophrenia are non-communicative and often not willing to co-operate with healthcare providers and social support networks. In addition, the carer's of people who suffer severe schizophrenia have less energy. Caring for a person who suffers from severe schizophrenia is incredibly draining, it leaves little energy for other pursuits.
- **K**: In addition, those who suffer severe schizophrenia are often ignored by the community. For example, whilst the 'plastic bag man' of Toowong, Brisbane is of no harm to others, it seems to me the concept that he is not 'harming' himself is difficult to reconcile given he is left to sit on the footpath surrounded by plastic bags, un-bathed and clearly in a state of diminished health. It baffles me why he is not given proper medical and psychiatric treatment. Is it because no one cares enough to organise this for him? Is this a visible result of the de-institutionalisation policy of the early 1980s? Who represents this man's interests?

- **K:** I think it is important to collate information regarding the needs of those who are least able to participate in the discussion. These people are sometimes represented by the Adult Guardian and the Public Trustee. What steps have been taken to obtain input from these offices as to what their clients' situations and needs are?
- **K:** I do not think the Commission can rely entirely on the representations of organised bodies. I no longer have an affiliation with an organised body, however I would gladly respond to online surveys on various issues. I suggest the Commission post online surveys on its website and provide sufficient notice to prospective participants of the existence of the survey and the deadline to respond. The surveys could be targeted to particular issues, e.g. housing, delivery of health services by the community mental health centres (you may even like to break this down to particular centres, e.g. Southport centre).
- **K:** In order to increase participation in online surveys, there needs to be greater community awareness of the existence of the Commission, the website and the fact that a particular survey is being conducted. I stumbled upon the Commission's website by accident when trawling the internet to deal with a pressing crisis concerning my brother. I no longer have a connection with a particular NGO and I am busy. However, if I was aware of the existence of the Commission and that it was gathering information which may assist my brother, I would gladly complete the survey. However, I also want to see the result of the survey upon its conclusion and the use to which the data is put (e.g. publication on the website of the resultant discussion paper). I am sure I am not the only sibling of a person who suffers severe schizophrenia who would not find this a valuable resource.
- **K:** Greater community awareness may be achieved by promoting the existence and role of the Commission through various means, talk-back radio, television, brochures in the Psych wards of hospitals, ask social workers to inform patient's carers and family members. These are just a few suggestions.
- **N:** Who - People with a 'lived experience. How – In a regular and consultative manner with the Queensland Mental Health Commissioner on a bi-monthly basis. These representatives with a 'lived experience' are drawn from a number (every) region across Queensland.
- **I:** As a carer, I don't have confidence that anyone is representing my interests in the process in the way I would like. That is why I have decided to become involved directly.
- **I:** Everything to do with Mental Health in Queensland screams to me to be dysfunctional, unresponsive and the precious few resources that are left within the public health system appear to only be able to operate in crisis mode.
- **I:** We are part of the West Moreton Integrated Mental Health system which really should be renamed the West Moreton Fragmented Mental Health System. While there are some exceptional people we deal with in the system the numbers have been savagely reduced over recent times, departments continuously restructured and workloads on individuals increased to the point the staff are barely able to respond to a crisis let alone have any opportunity to operate in pro active manner to try and reduce relapses by consumers.
- **I:** The number of beds in the Ipswich hospital mental health ward has been continually reducing for many years. There is no facility at the hospital (and I believe in all of Queensland) for mothers suffered any form of postpartum serious mental illness to be hospitalised with their young babies.



- **I:** Taking these any literally, dozens of other examples into account, I have no confidence in anyone being in a position to represent my interests as a carer and/or my wife's interests as a consumer in the system.

2. How should those representatives develop and maintain two-way communications with “grass roots” consumers and carers throughout the State?

- Praise for the Qld Voice newsletter acting as a clearinghouse for information, currently one-way communication.
- Use of media, Facebook, online to get all of the voices. Surveys.
- Use of YouTube – great for young people.
- Suggestion of engaging with people through chemists, GP's, psychiatrists.
- Without resources to send to every GP psychiatrists – take it to our own groups.
- Strategies that work at giving people the capacity to use their voice.
- Survey – peer workers sitting down with people at the end of a group and going through the survey.
- Social Inclusion week – conversations/discussion at groups.
- Mindful that poverty of carers/consumers can result in limited access to internet.
- Work collaboratively with university, TAFE.
- Working in partnership with each other – e.g. H of MIFQ said they would like to work closely with Qld Voice.
- **K:** I am not aware of any body government or non-government, which represents the needs of those who suffer severe schizophrenia. Refer to my above comments.
- **N:** These representatives have developed and maintained an involvement in Regional Mental Health and have shown a capability and interest in contributing to helping the system to improve and be better. They are involved in Government, non-for-profit organisations, service providers and individuals with a lived experience. They would attend monthly meetings in their region, and all regions need to have regular up-to-date way of communicating information to the wider community, be it through newsletters (hospitals and other), local papers, social media, internet, and radio.



- **I:** If Queensland Health, the Queensland Mental Health Commission and other involved parties are actually serious about receiving input on the current system and wanting to hear from consumers carers and families about the failings in the current system there is only one option available for true “two way communication with grass roots consumers and carers” and that is to employ dedicated personnel to fulfil the role of meeting with, communicating with, and truly understanding the issues that people have having a day to day basis.
- **I:** The current framework of government bodies and agencies and the plethora of NGO’s that are attempting to service mental health consumers and carers all appear to be operating as individual silos. Everyone is pushing their own barrow with little perceived interest in working together to provide holistic solutions to a very complicated problem.
- **I:** Again, I believe that for the Queensland Mental Health Commission to have any true understanding of the issues consumers and carers deal with on a daily basis, there must be dedicated personnel who sole job it is to meet with and understand the issues. Anything short of this only demonstrates a lack of true commitment to making meaningful, structural changes to an existing system that fails the very people it is supposed to work for.

3. What do consumers, and carers see as a “better system” (of mental health services) and how do we get there?

- Services to work complementarily with each other - currently seem to work in competition.
- Engagement strategy to empower and inform.
- Payment and support for consumer/carer representatives on consultations.
- Government view of ‘support’ currently narrow e.g. taxi voucher, \$25 to attend a meeting broaden it by providing support training such as PeerZone.
- Peer workers need mentoring and supervision how to stick with it, avoid burn out, cope with power plays and politics within health.
- Expanded therapy options such as CBT – talking therapies, nutrient power therapy – bio-chemists.
- Transparency and accountability.
- Eliminate System Gaps: e.g. advocacy.
- Need a road map of what paths are available – overview of ‘the system’ pharmacy, GP’s, hospital, support groups, CAG’s, NGP’s and peaks. “You are here” map.
- Understanding of rights legislation and advocacy process.

- **K:** I refer to the paper prepared and submitted by Queensland Alliance for Mental Health and the paper prepared by Browne, G, Courtney, M and Meehan, Type of housing predicts rate of readmission to hospital but not length of stay in people with schizophrenia on the Gold Coast in Queensland (Australian Health Review Vol 27.No.1, 2004). The message is clear from both these papers: There has been insufficient evidence analysed and insufficient data collated to enable any organisation to devise a “better system”. I would add to this my utter frustration at the lack of funding made available to provide a “better system” of mental health services. A better system will be devised by a collation of programs proven to work because they have undergone an evidence based assessment. There are worth programs in place now, for example, Stepping Stones in Coorparoo, Brisbane which provides psychosocial support to high functioning schizophrenics, and employment and training support. However they have just had their budget halved which has caused distress to a many of the program’s clients. Forgive my cynicism but it seems disingenuous to ask the community for input into “a better system” while government has failed for years and years and continues to fail to provide the resources to guarantee the continuation of current programs. Show me the money and the will, then I’ll devote my energy to providing my contribution as to what a “better system” may look like.

- **N:** What – A ‘better system’ is always about listening, respecting and talking with the person/s with the ‘lived experience’. Working and walking along side the person/s with the lived experience, for as long as it takes to enable the person to be confident to do or be for themselves. Recognising the uniqueness and opinions of those with a lived experience. Being open to different ways of treatment, have open dialogue and transparency in all dealings. Information recorded, information on medication and its side effects. All information readily available on request by the patient, advocate or allied person. A better system would also address other health concerns, as well as, substance abuse. Initiated programs and support whilst the person with a lived experience is in care. They do not leave care, until they have knowledge and a clear understanding of their substance abuse, and its adverse health effects, and they have already been on a program of withdrawal, and they will have on-going, hands on support after they leave the care facility.

- **N:**How – By starting at the top and auctioning changes. Standardisation of known methods that work – gathered from hospitals and other facilities across the nation. By ongoing education of new and maybe, not so new, ideas and methods that are available on medication, complimentary and alternate medication and methods. Consistent consultation with people with a lived experience, be they carers and consumers.

- **I:** I have what I think is an unorthodox approach here. How many NGO’s are there in Queensland being funded by Federal and State contributions? Does anyone even really know? Every single NGO that operates in this field has a level of management and administration. Some of these NGO’s have very small target markets or are simply not advertised or known well enough in the community to be helping more people. How much money every year is being spent by these small almost niche providers every year to pay for;
 - o Building, offices and vehicles;
 - o Wages for CEO’s, General Managers and other non “front line” staff.



- **I:** For each NGO is we work on \$50,000 p/a for building rent, utilities and insurance and then another \$250,000 for wages, vehicles and on costs I get a figure of at leafs \$300,000 per annum in overhead costs. If there are 30 NGO's (there is actually more but lets work on this number), all of a sudden we come up with \$9 million per year being spent on duplicated administration staff.
- **I:** I have worked in Senior Management for 20 years so before people start to try and shoot down the argument I understand that with restructuring and reduction in the number of NGO's we wont save the whole \$9 million. However I don't think it would be unreasonable to expect at least half of that could be saved and used in other frontline services such as beds and nurses in mental health wards or case managers from consumers.
- **I:** Other ways the system can be better is to simplify things. Have all support services under one umbrella. Hopefully then once someone is in "the system" the support personnel around them may have some chance of finding help through the various different services that are provided. I can't believe how little professionals working inside the mental health system appear to be. I have lost count of the number of times I have for a referral to a, b or c and been met with a blank stare and an "Umm, I don't know..." If the professionals working inside the system don't know how to refer consumers to appropriate support services then we have a system in melt down, in complete crisis which is what many would say we currently have in Queensland.
- **I:** In summary, my thoughts are a streamlined, simplified system with a single point of contact for the consumer to access any and all help and support they need. This will involve a significant increase in the number of highly skilled and trained personnel but I have a reasonable level of confidence that by taking a more proactive approach to management and recovery that the additional upfront costs would be offset by considerable savings at the "crisis" end.

4. Who represents the lived experience paid and volunteer workforce that is so important to the sector?

- Strategic area for development of the workforce.
- Consumer/carer consultants 19.5 workers throughout Queensland Health from 44 a few years ago. Was supported through the directorate – section since disbanded. Need for proper reflective supervision for these workers. Used to be a yearly forum, monthly meetings – now gone. Consumer companions 87 throughout the state.
- Peer worker - a lot of consumer workers in the hospital system also have strong connections in the NGO sector or community groups.
- Peer workers in the NGO –have similar issues to those in Queensland Health – could have same representative group.

- **K:** I do not know who represents ‘the lived experience paid and volunteer workforce.’ I am not even sure what the term means. If it means ‘who represents the paid mental health nurses’ I can say I knew quite well a mental health nurse who joined a community mental health centre in Brisbane only to leave shortly after because of the lack of support provided by her manager and co-workers. On her arrival she was given the most difficult cases and was not provided with any support by her manager (who if you believe my friend (and I have no reason to doubt her) seemed to spend most of her time ‘out the back’ ‘having a ciggie’). This nurse was contentious. For example, she would go to collect patients from their home and bring them to the clinic for their injections when they refused to come into the clinic voluntarily. She worked hard, burnt out and left the sector. There was no support for her, no representative body. I can say also from my own experience the level of support provided to and communication with sufferers and their families by the mental health community sector is very low. My brother was allowed to avoid receiving his medication by the community mental health centre on the Sunshine Coast who at one stage lost his file and would not ever communication with me regarding my concerns for my brother. The result was my brother’s psychiatric health deteriorated and he was removed from his living quarters (a boarding house). The paid mental health community must be properly supervised and be brought to account for their performance. In addition, the difficulty of their job should be properly acknowledged and reflected in their remuneration. Yes, it comes down to funding again.
- **N:** Who – Representatives with a lived experience in their particular region. The person organising the paid and volunteer work force for the region. Representative from the office for the Commissioner of Mental Health in Queensland. Representatives from Service providers.
- **I:** I’m not sure that any single person or body can represent adequately such a geographically, culturally, medically and socially diverse group of people.
- **I:** From a carers point of view I think ARAFMI do a reasonable job but I really can’t think of anyone that represents the consumers in an impartial way.
- **I:** I am very cynical of the NGO’s as they all have their own barrow to push to ensure they continue to receive funding from year to year.
- **I:** Over the years I have found some exceptional people in the Mental Health system. I would love to see these people, the ones who really care, have their voice heard. My experience is that the ones who do care are often beaten and bruised by a system that actively discourages anyone form acting as an individual or not accepting “the system”. The whole system needs to be turned upside down so it is consumer and outcome driven rather than process and system driven.
- **I:** Please listen to the front line staff within the mental health system. If the Queensland Mental Health Commission really wants to know what’s happening, talk to the nurses in the mental health wards about the pressure to get people in and out as quick as possible because there will be someone who is just that little bit more unwell who will need the bed come around the corner tomorrow or the case manager who has a 100 people he is supposed to see on a regular basis ranging from those recently discharged following an acute episode or relapse to those that have been well for some time.



CAG's

- All of the hospitals have a CAG. Praise for metro north CAG.
- Some hospitals have no CAG or the CAG is not very strong. Accreditation of CAGs there is a flurry of activity, which then dies away until next time.
- Relevancy of CAGs went down when consumer carer consultants workforce started as hospitals began to sideline CAGs – instead engaging with their peer workforce as representatives of carers/consumers.

Training

- Modules in Cert 4 of consumer development but no one has actually developed them – some of us are bound by the places by we work.
- Norm W is working on a taskforce developing module to run the Cert 4 Peer Work on a free basis – will be run mid to late next year.
- Cert 4 Peer Work will be great and will fill a need but will not fill all the different needs.

Advocacy

- Queensland Advocacy Inc
- Qld Public Interest Clearing House
- Public Advocate
- Self advocacy – developing consumers voices
- Sisters Inside example of use of PeerZone workshops on how to uncover own voice and deal with drug/alcohol mental health accommodation issues. Voices of the homeless. PeerZone useful way of gathering those voices.

Commissioner:

- When the first 3yrs of the commission are up, will report in one of three ways:
- I think the commission has done its work because...or
- we got this far and you need to continue on in this way withor.....we tried this. but it didn't work and suggest this way forward.....
- Commissioner's advisory council will include at least one carer and consumer and there will be one or more sub-committees formed. They inform her but she takes the decisions.



- Commissioner said it would be easy to cut and paste and come up with a document to be signed off but there is no ownership with that. Her document goes to government by the middle of the year.
- Are your voices getting through the system?
- Challenge is not to pour more resources into the system for more of the same but interaction between the services – change the face of the system. That is where the extra funding is needed.
- OK to have many doors but which is the main door?

Qld Voice:

- Formation: QCAG in the directorate was closed down and Qld Alliance was tasked to form Consumer and Carer group, which eventually became Qld Voice. Established 2008. No funding since 2012.
- Qld Voice unfunded - currently cannot to any degree support carers and consumers.
- Qld Voice to have telephone conversation with those that didn't attend forum.

Other Comments:

- Queensland's Anti-Discrimination Commissioner has had meeting with organisations, gathering information and preparing for the review of the Mental Health Act.
- A consumer commented that wanted to see Mr Newman here tonight – need for funding.
- Consumer – public health system is sick. Nurses used to be able to spend time with consumer but now absorbed with paperwork and consumer needs to seek them out.
- We are all disparate groups – commonalities?
- Diversity/representation through access to statistics where are the pockets of people. Harvey Whiteford has head around statistics.
- Expanded options for assistance with carers.
- Support network.
- Priority setting.
- Workers compensation a system that creates/exacerbates mental illness.
- The existing MH Act needs to change the Justices Examination Order to ensure involuntary assessment and treatment is not imposed unnecessarily or maliciously.
- There needs to be a better way for people to access care.
- **K:** My background is that my elder brother was diagnosed with Schizophrenia in or around 1972. He has been severely debilitated by the illness and the medication does little to alleviate his symptoms. My brother is so sick and delusional, his level of functioning is very low. As a result of my



involvement with the Schizophrenia Fellowship of Queensland I made friends with a number of people who suffer schizophrenia. However, my friends are high functioning and, as a result, have been able to access the various services offered to them by government and non-government organisations alike. Unlike my brother, they live fulfilling lives. Whilst, more can always be done for those who suffer mental illness, my grave concern is the needs of those who suffer severe mental illness (schizophrenia) are 'covered over' by the needs of those with less severe but more 'trendy' mental illnesses (e.g. depression). A good illustration of my concern is the conversion of the Schizophrenia Fellowship of Queensland to the Mental Health Fellowship. The Schizophrenia Fellowship was established to give voice and support to those who suffer schizophrenia and their carers. It has been overtaken by a broader support objective and I fear this is to the detriment of those people who suffer severe, untreatable schizophrenia, such as my brother. I will limit my responses (below) to the very narrow focus of people suffering severe schizophrenia because this is the group with which I have contact.

– **K:** Provide sufficient funding to:

1. Clearly categorise the types of mental health illnesses suffered within the community.
2. Clearly categorise the severity of each mental illness within the community.
3. Examine the needs of each type and each level of severity of mental illness within the community.
4. Properly assess the effectiveness of current services provided to each type and each level of severity of mental illness within the community.
5. Properly fund and guarantee continuity of funding for the programs which have been shown through empirical analysis to provide an acceptable level of service to its target group.

– **N:** I go back to Q3 how – the mindset and the culture of how a mental disturbance is raised ?? from the top needs to change. People who are overwhelmed with a mental disturbance or episode, need to be offered our compassion not condemnation, given understanding and support whilst they are experiencing these typically overwhelming, feelings of fragmented identity, humiliation and helplessness. There are other ways. Long term use of highly toxic medications has never been the answer.