

Count Me In: Year 2010 tea room conversation on Routine Consumer Outcome Monitoring in NSW Mental Health NGOs

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ABSTRACT

A six month period of enquiry (the 'preparing readiness stage') with consumer leaders, management and staff of specialist mental health NGOs in NSW, has concluded that they appear willing for the sector to develop and manage a system of Routine Consumer Outcome Monitoring (RCOM). They are willing but are not ready. This paper provides a visioning exercise of what the components of a RCOM system in the sector might look like after implementation: a hypothetical conversation between two staff members of a hypothetical NGO. The presenter draws upon the feedback raised by NGOs, not about whether RCOM should be done, but how it is best implemented and where to begin.

INTRODUCTION

MHCC's vision for RCOM was first put in 2001 as a recommendation of the MAPS Project.

It is the year, 2010.

In 1998 Victorian NGOs in mental health reported growth from \$16.9M to 30M in two years, being 14% of state mental health expenditure, thanks to RCOM.

Mary is about to return to Good Life Inc after 2 years paid maternity leave. Maternity leave is paid now because NGOs in the NSW Mental Health NGO Grant Program were given three times the 2007 funding allocation, which they top up with their own schemes. NGOs also had two rounds of Infrastructure Funding. The first round helped some NGOs improve computer facilities and the latest round was specifically to help them utilize the outcome data they have collected since July 2007. Many commissioned external evaluators to review interim reports and compile evaluations using three years of data with recommendations made for service redesign.

Mary is thankful, because vacancies in mental health NGOs these days are hard to come by. NGOs are viewed in the industry as innovative and able to get results for consumers. There is high demand for any positions and NGO programs are attracting increasing research attention and the sector has its own Research Evaluation and Development Unit. In the tea-room Mary seeks an update on changes during the maternity leave with a colleague, Sue.

RCOM AS CONSUMER-FOCUSED

Mary: 'I saw Good Life on ABC's Lateline recently getting the PM's award for self employment programs amongst people with a psychiatric disability. Lateline said that some of our clients have moved off the Disability Support Pension... It said, 'consumers *self select and stream themselves* into this program' – what did that mean? How do we do that?'

Outcome tools can be consumer-rated or worker-rated. RCOM in NSW Mental Health NGOs is encouraging the uptake of consumer-rated tools as a minimum.

Sue: 'We don't, service users do really, but with a bit of our help. We provide the encouragement and the framework. Service users complete outcome tools (she points to a computer in the foyer) to monitor their own recovery. They complete tools when they first meet us, and again six months down the track and again for an annual review. They also use them whenever they leave the program. Each interview room has the system — see the computers with the pink manual next to them? But if service users prefer, they can just use the paper-based forms and we enter the results of what they write into the computer for them.

Mary: What about clients that come once or twice, then never again?

Sue: All agencies will have these clients. Sometimes just knowing a service exists for support helps them. For those that elect not to come again, we post them the follow-up outcome form to complete and return to us. They don't seem to mind this and it gives them a chance to say why they didn't show up again. Sometimes its not because we failed in some way, but because coming just once helped them in some way, perhaps even to realize they can make it ok on their own. But this is still a tiny 'outcome' that could be captured.

Research shows a gap between what workers think they deliver and what consumers say they received in an interview.. Outcome tools have been said in consumer consultations to make more real for the consumer the focus and purpose of the interview.

After service users complete the tool, they are invited to chat with us in a formal way about how they are going and what they want in their lives. We go item by item through the things they wrote and considered when completing the outcome tool. That is, they discuss with us what the outcome tool prompted them to think about and plan out as short and long-term goals'.

Mary: Does this replace the initial interview and the usual procedures we do in the Individual Service Plan?

Sue: No, it is an add-on to the initial interview. It adds value, depth and provides discussion pointers for the ISP. It helps build rapport...

Rather than supportive interviewing alone, which, when you think about it, must just seem like mere chit-chat to them, we structure it more these days to personalize the relationship. We spend more time with them not less to enrich our helping and their helping to themselves. ...

We have found that service users start to apply the items on the tools to their own health or wellbeing and they realize they are in control of their mental health and their lives. The outcome tools give them a language for communicating about themselves and takes some of the conceptual mystery out of what we view as 'mental health' and what they are experiencing as 'recovery'. Even embarrassing questions are covered'.

Consumer consultations report that outcome tools can break the ice and make it easier for consumers to raise hard topics for discussion.

Mary: 'Tell me more, this is new for me. Outcome monitoring is standard within the method of research papers, but we are not taught how to use these tools in a social work degree'

Sue: 'Few health disciplines actually train people in undergraduate degrees to use the tools in practice, except if you do some psychology modules or in the other social sciences, the tools are used in research. That is why we prefer to have clients use consumer-rated rather than worker-rated tools. Research shows consumer-rated tools are reliable and valid and they enable clients to speak for themselves. Getting back to the Lateline question: clients realise that they can **stream themselves** into other services or programs, here or elsewhere, when they understand their needs better – it might be a year down the track after several reviews, or a few months down the track. They can chose programs that may facilitate not just recovery but having a good life. After all, we only get one life. That's the explanation I use with my clients anyway, that the process of using outcome tools is to be informed so you can be more empowered to shape the best life possible.

MHCC's state-wide Consumer Consultations found that consumers in NSW want outcome tools used by NGOs to focus on strengths and aspects of life other than health care and mental health symptoms. This implies multi domain outcome tools should be selected by NGOs.

Here is an example. We have now learned at Good Life Inc that meeting users' economic interests and needs is as much on their agenda at Good Life as their health care. We've gone from poverty amelioration using band aids to helping people in self employment and even learning about the stock market for some clients. Some clients have not changed at all, but they

appear to appreciate being offered tools to make more tangible why they are using our service.

Outcome tools can be used both descriptively (to describe service users) and evaluatively (to evaluate service use and outcome for the consumer. Outcome tools help an NGO know who they are assisting, the nature of problems, when more or less help is needed or when help is no longer needed at all.

We realized that clients here needed a way to shake the identity of being 'psyche disabled' which need not dominate their life. Now a group of them identify as 'self employed'. Others identify as cooks and voluntary workers in a charity and so on. Those who have graduated through all their goals which were the focus of their recovery and our work with them, sometimes elect to stay in touch with us, but without having active assistance from us. Some continue friendships with the clients here and come to the Christmas party, but they don't elect to use our active, intensive program. The outcome tools help them know when to tell us when they don't need us any longer....

Instead of service users seeing themselves as psych disabled for life and just attending here for what we used to call, 'socialisation', they are now really getting out there and participating in the economy or in things that can help them feel a part of society, not just a member of our association or service....

Remember Sally? She had been with us for years. She left in 2008. She is not a client any more in the active sense. She comes back now only to give evening seminars once a quarter to other consumers in this region on GST in self-employment. Consumers from PRA, Aftercare, Care Employment and Catholic Health Care come along as well....

You remember Harry who came here for years? We never picked up his gambling addiction until we used outcome tools. He is now much improved after specific gambling addiction assistance which we didn't give, but the Mental health team did when we alerted them to his problem'.

PROCESS ISSUES: INVITING CONSUMERS TO USE OUTCOME TOOLS

Mary: 'How did you get consumers to participate in using outcome tools in the first place?'

Sue: 'We just invite them to do so when we first meet them. We explain it to them. Plus we tell them that it sometimes helps to get more funding if we can show that people are assisted here and experience even small changes in their lives and that the forms monitor these changes. We tell them the forms include questions about the whole of life and are not just about symptoms. We make sure they know participating is optional.

They also have their own consumer seminar series supported by MHCC with guest speakers and convened by consumer leaders. This helps them to understand consumer self-assessment using outcome tools to monitor their recovery. It has become a norm now. Consumers sort of expect it from many services.

Mary: I know if it were me, first I would want to tell a worker what I was feeling. I would not know my own needs necessarily, especially if I was upset and still confused from psychosis. So I would want to be heard in the first meeting, whether or not I filled in a piece of paper — so, so long as they talked with me and listened to me first, I would then complete the piece of paper as a reflective exercise unless I was a mess and in a crisis. Thereafter I would want to spend more time with them getting them to understand me better and I would feel they took me seriously with the work we wrote down together. I would feel good if they listened then read what I put down. I would agree to participate especially if I knew better services for others might develop from seeing if a program really helps a person's life chances and outcomes that matter.

Evaluations of state and territory implementation of RCOM report that process matters – ie the process of how you invite a consumer to participate in using an outcome tool. Done well, rapport building leads to improved assessment and thus, to improved need satisfaction. Good process = consumers better understood, = better served = complete data collection (because consumer agree to use it).

Sue: That's right. It is about not being smug and dismissive of them which we can fall into after years of experience. Its about social inclusion really. We put it to consumers that we all get only one life and we have to make the most of it. We don't want their recovery to be about our guess work, even educated guess work. Even when we complete worker-completed outcome measures, they are objective and take some of the guess work out of assessment, getting to know each other, communicating effectively and enables us to focus on key aspects of what constitutes a good life, from the consumers' perspectives. In addition the tools give us a measure of results for that person or for a whole program if we take all consumers together. We can for example, retrieve information to ask ourselves, how are all the people aged 50 and over doing in our programs? Having evaluation data, rather than just doing an Individual Service Plan that does not report a measure of change, modernizes our thinking and planning of better care...

We found that most consumers said, Count Us In. Whether they see their needs as being about getting work, finding more leisure, connecting with people and making better friendships, improving their material wellbeing or about symptom control and preventing relapse, the multi-domain outcome tools are broad enough to really capture a description of clients far better than unstructured or semi structured initial interviews can alone.

We discuss it together and iron out any difference of perception between what they want and need and what we think they want and need.

One study of Victorian NGOs (Trauer et al) found a higher rate of participation than some public mental health services which may be around 60% participation (Pirkis et al 2005).

COMPLETENESS OF DATA CAPTURE

Mary: How many take part now?

Sue: About 90% of the consumers use the outcome system. Some with intellectual disability also use them, but others don't get it. We offer it to 100% of consumers and walk them through this Good Life Inc brochure explaining it.

Mary: 'But I won't have to use this outcome system will I because I run groups, not individual sessions?'

Sue: Mary, everyone uses it here. You had better get with the program by watching others apply it so you learn how. Just because you run groups doesn't mean there is no individual benefit for participants, and it doesn't mean you cannot adapt groups to be sensitive to the needs of individuals in the group. We aim at Good Life to have before during and after data on as many clients as possible to help us help as many people as possible as well as build program evaluation capacity.

POTENTIAL USES OF OUTCOME DATA FOR NGOS

As with any quantitative (statistical) evaluation, data will be of more use to the NGO if more clients participate.

Sue: Lets recap on some key concepts. Each individual starting your groups should be offered an outcome tool, lets say, the CANSAS, and if they only stay one or two sessions, it doesn't matter. It is better to capture what they needed by coming to Good Life than capturing nothing about them at all and perhaps over time, you might learn which consumers tend to leave, and which consumers tend to stay. There may be characteristics setting these two groups apart. You might then try to alter the program for those who tend to leave, lets say, by developing a separate program for their needs, or by making sure the first session tells people about alternative programs so they just don't leave and are unserved entirely. For those who fill in an outcome tool after participating in the groups for the number of weeks or years intended, you might also learn about the precise benefits of the group, or who groups best help, or how many weeks a group needs to run for before it changes direction or content. We start to apply our professional judgment and skills and become evaluators of our own programs and the questions we could ask about our own performance and service could go on and on. See how the use of outcome tools stimulates our questioning and thinking. They build an evaluation culture within the agency.

....Incidentally, you will be surprised how much the consumers take charge of the groups now. They like the fact that the tools give them more of a say and help them prepare their thinking for participating in the group.

Policy advocacy is a key role of NGOs. The quality of this advocacy may be enhanced if informed by information about the results of NGO alternative programs or partnerships.

It was one of your groups where clients got together the delegation to the Minister to report the annual outcome data of Good Life Inc directly to her. Service users across the region plan to do this on behalf of their association Boards each two or so years. **Results Informed Advocacy** they are starting to call it because now policy advocacy can be informed by credible data rather than just a wish list or an ambit claim for more funds.

There is still a human rights claim to a minimum level of funded services whether or not there is data in support of it, but governments should encourage programs that show their results and which can argue convincingly from the data why programs should be strengthened in particular areas. This includes programs where consumers are not progressing and are still not having a good life despite attending services. We need to address this disadvantage through relevant data that can help us design better programs.

Mary: Does the Health Department get to see our data and results directly, say with access to the data set?

Sue: Absolutely not as far as direct access goes because we are an independent sector and client data is confidential. But absolutely yes, is the answer, as far as health departments go for getting, lets say, de-identified reports from the data system. While they do not manage our data it is reasonable that they be informed and assisted to plan public sector services in partnership with us from knowing what mental health and other social gains are achieved from our programs, as evidenced by the outcome data we generate. ...

Many stakeholders have a genuine interest in what NGOs do and how they help people. These computers were funded by the Small Business Council for example. Once they saw what we were achieving they funded four consumer scholarships per year in external employment that requires study. That such an organisation can help us in this way to look after all the computers, helps us to sustain our outcome program.

The important principle is that the data collection is ours at Good Life (consumers' and the service) and we do provide annual reports to Health as we have always done, except the reports are better informed now by objective data that are more efficient to generate. The reports tell a clearer story about

our work – not just activity data, but where we get results and where we struggle and what the challenges are. Health can also request information. Different sections with the Health Department have an interest in the data, for example, the youth branch may like to know who we serve aged under 24 years and what problems they experience and have ameliorated by coming here.

TRANSPARENCY, BUILDING AND DISSEMINATING THE NGO KNOWLEDGE BASE

RCOM requires gradual capacity building and is a long-term commitment.

Mary: What is this journal article here?

Sue: That's MHCC's and Good Life's most recent paper in the International Journal of Psychosocial Program Innovation showing our learning over the three years since we started this routine consumer outcome monitoring in 2007. It is about the feasibility questions we managed to resolve and the gradual capacity building we achieved across many sites.

MHCC is also writing a new paper on outcome monitoring systems as policy advocacy tools for NGOs. Our network has critiqued the first draft. But this is a bonus use of the data over and above key practical use of it for improving consumers' lives. Different NGOs in NSW have now published five articles in peer review journals since 2007 on their use of their outcome data.

Mary: You are telling me that we have networks to review journal articles, that we write in our own sector? But we are not 'researchers', we are very time-poor, practical people in this sector!

Sue: Who says we cannot bring practice and research together and close the gap between putting our own research findings into practice and build better practice from our research and that of other people? Outcome monitoring gives us an evaluation infrastructure that there is no point having unless it is used to learn, grow and help people better as workers and as organisations....

There is a line to be drawn however, about evaluation 'on the run' with routine data collections and what we consider 'research' of a quality for external mainstream publishing. Occasionally with extra effort and rigor, and some outside consultants or Health sector input, we have generated more robust papers that are really 'research'. About research in the community sector by the community sector, we say, Count Us In.

MHCC's Research Evaluation and Development Unit (RED) provides collaboration between NGOs to ensure the data is sound and is available to NGO boards to inform their service development. If we add in some funded research time, we can use the data and take the time to flesh out what it is telling us and what questions of ours it answers. This is fundamentally different to collecting data and sending it to health departments, and us never knowing what it means to us, as opposed to how health departments might use it. For once we have a system that we own and can relate to rather than just provide data to third parties for their use.

Mary: So you are telling me that we remain values based organisations, but that RED has become a value and that we can have evidence and outcome-informed programs of our own within values based organisations? Boards of management might run the values and policy advocacy agenda, but as program staff we have to run evidence-informed programs that we continuously evaluate and improve. That's reasonable.

And what you are saying is that with cooperation between networks of similar sorts of NGOs combining evaluation questions somehow we find the time to get occasional reports into the peer-reviewed literature? Its an extension of the existing cooperation and horizontal alliances NGOs have always enjoyed?

What you are also saying, if I have understood you right, is that it has become an ethic to describe what we do and who we serve to the wider stakeholders, international providers and consumers of psychosocial programs and not just association members or the funders. I like the sound of that because we have the benefit as workers of more stimulation through our work.

Mary: Tell me Sue, how did MHCC get our data?

To systematise RCOM for mental health NGOs will require data agreements.

SYSTEMATISING DATA MANAGEMENT - 'DATA AGREEMENTS'

Sue: We have a data agreement with MHCC signed off by our Board and their Board/CEO. Essentially, some agreed items of data flow from our computer system in a client-de-identified way. It is sent to them on the 30th of every 3rd month. This got going in late 2007 once the sector agreed on which minimum data set items were relevant across the field of NGOs in mental health. To this we added some key outcome data, for example, the results in each participating NGO's CANSAS scores for the clients served in the period, and 2 other tools used by many of the service provider NGOs.'

Mary: 'Is it much extra hassle?'

Sue: 'Some NGOs have their quality manager do it and be responsible for data reporting. Others have set up a proformer that the clerical staff complete and send it through to MHCC. It only takes a minute to report this to MHCC's system, because the system at MHCC was set up with compatibility.'

...When you begin to think about this State-wide collection of data, you have to shift your thinking to a new level. MHCC can provide independent review of the data set across the State and provide more analysis than we get time to do for different groups of consumers with characteristics or needs in common. That is, they see the data through fresh eyes and ask quite different state-wide questions than we do, for example, which regions of the state may need different services, or which kinds of new partnerships are needed to meet unmet needs, or is the size of the NGO relevant to the outcomes being achieved for different groups of consumers?

....The MHCC RED Unit provides telephone support if we get glitches in our own data collection or use. They also convene seminars to help our staff understand our results. Their Learning and Development Unit provides accredited training for entry-level use of the program and all the staff are really helpful.

Lets have another coffee. I have only 10 more minutes to go through this stuff with you and then I have to get back to work.

....We are one of 44 NGOs who collaborate together and send our de-identified data (with consumer consent) from our own system using a feature to feed data to MHCC quarterly. 32 NGOs are soon to come on board.

It is no extra work for us to have MHCC house the data collection from many NGOs. You need to read the data agreement Good Life Inc Board has with MHCC.

RCOM systems
require quality
management

SAFEGUARDING THE USE OF DATA

Mary: Who is allowed to report on the data at Good Life Inc? For example, who is empowered to draw conclusions about what it means and what we could do in response to it? Isn't it possible we could misuse the data and make the wrong program changes?

Sue: We have written protocols here about that. You can use the data to inform many evaluation questions if you have the

capacity for analysis within your program. But most group-level data analysis is managed by our RCOM Management Team here at Good Life. Workforce mix sort of determines who can use the system at the point of analysis. But all staff can discuss reports and on some issues we can respond straight away by making minor program modifications.

...On some issues such as making policy changes about the type of programs we run here overall, or about changes to who attends, for how long and larger questions, the RCOM management team compiles a report for the Executive and the Board. It is a routine report now in our annual strategic review days. Some of the data is used for tenders as well. So as an organisation we share insights from the data before jumping to conclusions about it and in some cases the RED unit assists our interpretation as does their Expert Reference Group.

Getting back to consumers. They took up the most important issue: actually using the data personally to find markers for independence, hope and encouragement. Old identities as 'psyche disabled people' were more easily replaced as they see their strengths more. Consumers started to make use of the information immediately. This makes it worthwhile alone.

As an organisation it took us two to three years to get real valuable information from it and to start to use it for service improvement'.

TRAINING AND SUPPORT

Mary: 'So, how do I use the system. I have had no training but I have a grasp of how outcome tools are used in the public system from my experience there a few years back?'

Sue: 'First, you need training on our system, it has a different purpose than MHOAT... even though HoNOS is a multi-domain and excellent measure, the clinicians are seeking to resolve symptoms and especially risk in relation to particular depressive symptoms. While we are concerned about symptoms and don't want clients distressed by symptoms, our task is to help them get a life regardless of symptoms. We use different outcome tools.'

Some NGOs have a data agreement with Area Health Services that for shared clients, the MHOAT data flows to the NGO for client review meetings with the consumer, but this is further informed by the NGO data collection, which is often about the strengths and capabilities of the consumer not just symptoms'.

The relationship of MHOAT to RCOM in NGO mental health programs is important for the quality improvement of collaborative care and for effective and equal partnerships. RCOM can inform structured shared care.

We don't duplicate collecting MHOAT data. The fit with what public sector mental health services and GP services are doing to monitor health status for consumers, is covered in the Initial Training.

We have a system of training here at Good Life once you do the MHCC Familiarisation and Initial Training. You can also elect to do the Leadership Executive training if you are a program manager. There are two intakes per year for the face to face one day Initial Training at MHCC and this is supplemented by structured supervision and assessment at Good Life Inc. Everyone is encouraged to do something else each year as **continuing education**. This might be going to an evening seminar on outcomes, doing and writing up a **Quality Activity** using outcome data to improve a program, running a seminar for Carers on how Good Life contributes in the community but **using the outcome data**, again de-identified.

MHCC provides training whether or not the NGO is part of the data agreement. It is the conceptual framework using population health principles regardless of the program purpose of each NGO that is essential to grasp if we are to truly use the data. We found that Good Life could easily relate to the framework and situate our work within part of the population-wide Continuum of Care. We have to see service users as having their own life and self-management and also as moving between agencies, in and out of independence, in and out of systems of assistance. It is about improving whole systems of care ultimately.

After the training you become a registered user but you have to pass the assessment. There are choices about this but a lot of us have done a **Quality Circle with consumer educators**. They are great because the consumer educator gives us feedback about our approach when inviting consumers to use the system and about how good we are at walking with the service user in planning for their needs.

They go gently gently and appraise how we come across when we interview and engage consumers in a first and follow-up interview using the outcome tools. The consumer educator is a simulated service user while another consumer educator is an observer or we can have a peer or our supervisor. I took all these skills for granted thinking I was wonderful just because I'm an OT. But the Quality Circle made me more focused on my communication and gave me more confidence in seeing things from the consumer perspective. It led to my better use of the outcome tools and my sensitivity and confidence increased.

There is a website and an RED Unit now at www.mhcc.org. There is a series of Frequently Asked Questions that tells you what you need to know and provides the training resources.

Mary: Can I get familiar with the system prior to training?

Organisations with evaluation infrastructures and with outcomes cultures can more effectively determine their destiny as agents for service improvement and of social change. With outcomes systems they are able to determine strategic directions for meeting public health needs and can participate in public health and social policy debates.

Sue: Of course! You can start using it now with your supervisor, but you still have to attend one day of the MHCC training and become a registered user because our NGO is a signatory to a data agreement with MHCC.

CONCLUSION

Mary: NGOs seem to have done well by counting everyone in to the RCOM system with consumers in the driving seat, and it seems we now have a system to inform us how to serve better. At the service system level it seems to potentially allow us to assert ourselves in an independent sector more as if the sector is in charge of its own destiny'.

Sue: Absolutely. We may be the third sector, but we are no longer the second cousins, so to speak, and while we continue to serve some niche needs unlike the public sector, we can also have greater impacts on community wide mental health needs either alone, or in partnership with other providers.

Mary: 'Count me in'!

NOTE: The specific components for implementing a system of RCOM for mental health NGOs is currently commencing consideration, so this hypothetical provides an **example approach** only based upon a review of evaluations of existing systems of RCOM. NGOs have had a six - month period of consultation further to the Discussion Paper, *Mapping the Difference We Make*(August 2006) about the concept of a system of RCOM for service providing NGOs.

NGOs and consumers will be actively consulted about further developments by MHCC and system developments, including training and support and IT systems, will be funding-dependent. An Expert Reference Group will be considering all feedback and advice from NGOs. Comments are welcome to Jenna Bateman Executive Director of MHCC or Jonine Penrose-Wall, JPW Results on jonine@iimetro.com.au

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