EXECUTIVE SUMMARY VERSION

MAPPING THE DIFFERENCE WE MAKE

NON-GOVERNMENT ORGANISATION USE OF ROUTINE CONSUMER OUTCOME EVALUATION IN PROVIDING MENTAL HEALTH CARE IN NSW

DISCUSSION PAPER

AUGUST 2006

Jonine Penrose-Wall

Mental Health Coordinating Council of NSW

NGO Development Strategy Series	WORKFORCE DEVELOPMENT QUALITY AND OUTCOMES ☑ PARTNERSHIPS

quality &

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outcomes

Mental Health Coordinating Council MHCC
PO Box 668 Rozelle NSW 2039
Phone: 02 9555 8388 Fax: 02 9810 8145
Email: info@mhcc.org.au Website: www.mhcc.org.au

AUTHOR

Jonine Penrose-Wall

Consultant Researcher, JPW Results. Literature retrieval and review, editing, expert consultation, structure, format and design.

CONTRIBUTORS

Jenna Bateman

Executive Director, Mental Health Coordinating Council.
Project Coordinator. Conceptual development.

Sarah Buxton

Policy Officer NGO Development Strategy, Mental Health Coordinating Council (to November 2005). Initial conceptual development, appraisal of measures, survey of non government organisations, sector consultation.

Tony Ovadia

Consultant Researcher. Literature retrieval, appraisal of psychometric measures, drafting and editing.

resiliency

recovery

rehabilitation

GLOSSARY

Consumer outcome

'The effect on a patient's [consumer's] health status that is attributable to an intervention' (Andrews et al 1994:12).

Evidence based practice

'Using interventions for which there is consistent scientific evidence showing that they improve client outcomes' (Drake et al 2001). A preferred definition is 'Evidence-based practice is the integration of best research evidence with clinical expertise and patient values' (Institute of Medicine 2001:147).

Process Outcomes

Measurement of the processes and structures of care defined at organisation or system levels around agreed standards (expressed as 'Performance Indicators' to monitor quality in the organisation).

Quality

NGOs apply QMS concepts of quality as follows: 'putting the service user first, inspiring vision and leadership at all levels, developing informed plans and making evidence-based decisions, teamwork, system-wide focus and continuous improvement'. A quality organisation 'improves service user outcomes, organisational efficiency, staff satisfaction and develops tools to benchmark and control costs'. In mental health, 'quality' is 'a measure of whether services increase the likelihood of desired mental health outcomes and are consistent with current evidence-based practice (WHO 2003:10, Institute of Medicine). Central to quality is that consumer expectations are met wherever possible and affordable.

Quality domains

NSW Health-defined quality domains include Safety, Effectiveness, Appropriateness, Consumer participation, Access and Efficiency.

Routine Consumer Outcome Measurement (RCOM)

Repeat measures of consumer outcome taken as part of the routine of the organisation and when staff and consumers aim to manage disease, disability or risk factors or aim to meet the needs that consumers have identified.

Screening

The use of outcome tools and assessment scales for detecting health problems, administered once to individuals within defined groups at risk.

R.E.D.

Research, Evaluation and Development. ('Research' as distinct from minimal information collected through Routine Consumer Outcome Measurement).

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FOREWORD

The Mental Health Co-ordinating Council Inc (MHCC) is the peak body for Non Government Organisations (NGOs) working for mental health in New South Wales. By late 2005, MHCC had 144 organisational members. Of these, 97 were providers of direct psychosocial-related services to consumers and carers. The remainder provide health promotion, advocacy, information, research and networking and some Area Health Services are members. The website lists all members (www.mhcc.org.au). Taken together, these organisations provide resiliency, recovery and rehabilitation programs across a broad range of social health and welfare domains vital for mental health.

MHCC's membership includes specialist and generalist community organisations. 'Specialists' formed for the purposes of promoting mental health, preventing mental disorder or to assist those with mental illness and disability arising from the illness. 'Generalist' (or multi-purpose) agencies include other human service peak bodies, church or congregational welfare providers who provide assistance to disadvantaged persons. In the latter group, significant numbers of their clients have or have had mental illness but may not have current or past contact with the formal mental health system.

MHCC member organisations comprise a diverse community of concern for mental health around which multiple consumer, carer, community and organisational interests must be taken into account when seeking to influence and support quality improvement. Both categories of agencies are invited to consider this paper.

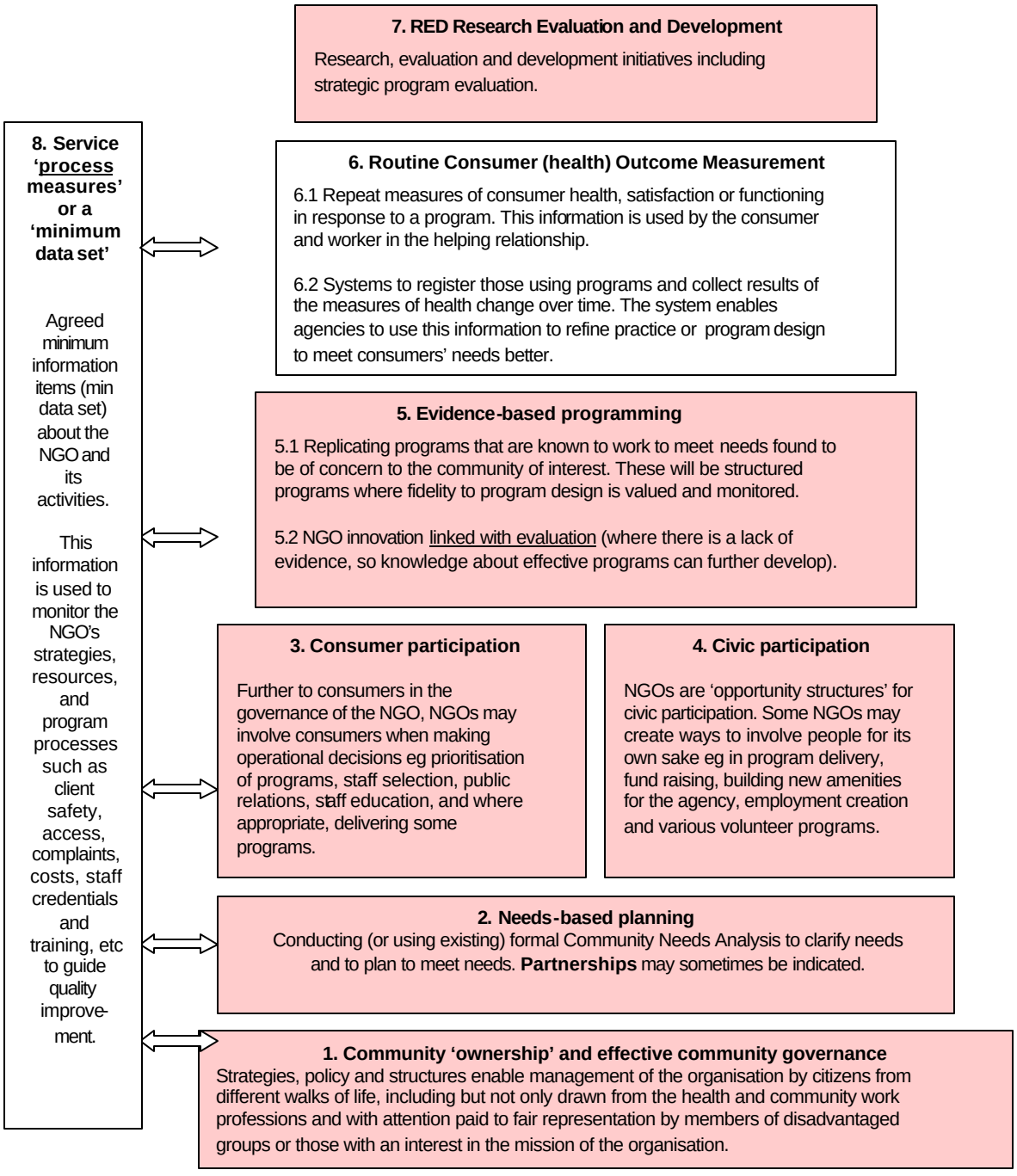
The paper has been developed as part of MHCC's Non Government Organisation (NGO) Development Strategy funded by the Centre for Mental Health, NSW Health.

Readership

This paper is intended for NGO Board and committee members and their consumer advocates and advisors, staff and volunteers of NGOs. It is also for discussion by policy makers and executives of Area Mental Health Services.

A QUALITY FRAMEWORK FOR NGOs

Figure 1: Potential components of a quality framework for mental health NGOs



KEY MESSAGES

- Consumer health outcome measurement has been called a 'movement', advocated as part of mental health service reform. It is now mandated for public mental health services Australia-wide.
- It has been voluntarily adopted by some mental health NGOs in NSW who report it useful for the consumers-staff helping relationship and for service review / development. Consumer-rated and worker-rated tools are in use.
- Victorian NGO psychiatric disability support services have used outcome measurement in a State-wide agreed way for around 10 years. They adopted routine consumer outcome monitoring (RCOM) earlier than their public sector counterparts in Victoria and nationally.
- RCOM may at first be applicable to about 21% of **programs** (not organisations) within NSW NGOs: those that are currently a) structured, and b) target individuals (rather than populations). Many are large programs and RCOM would provide vital information of public health interest and importance.
- NGOs can be valued for their informalities. RCOM should add value, not detract from nor bureaucratise the NGO's helping style.
- Even where RCOM is mandated, consumers are not obliged to use measures. The wishes and views of consumers will determine much of the debate about the future of outcome measurement in NGOs.
- RCOM can monitor outcomes broader than symptom change. Despite most NGOs not providing 'treatment', RCOM still has a potential role.
- RCOM must be quality managed, especially how results are interpreted.
- Presently outcomes from NGOs are not reported or collected in any systematic way. We don't know what outcomes most individual NGOs, or groups of similar NGO organisations achieve.
- RCOM requires leadership, team work, resources and long term commitment.
- RCOM is only one building block of a quality framework. On its own it will not address organisational quality management concerns.
- Organisations ideally use **more than one RCOM tool** because there is no one perfect tool that measures multiple domains of mental health outcome. Such tools work best in combination to give an adequate picture of consumer outcome.
- The Camberwell Assessment of Need really measures met and unmet need. This paper recommends trial use of this tool where appropriate to NGOs as it has been found a useful proxy of outcome for consumers.

"Outcome measurement is not the main game… Helping people is the main game. It requires relationship, acknowledging the person as a person without which there is seldom health gain.

Outcome measurement will only add value if it is not applied to exclude people from services nor to constrain NGOs in developing new forms of services. If used well, it may help them develop new forms of services".

Emeritis Professor Ian Webster AO, Chair National Advisory Council on Suicide Prevention, Physician, Matthew Talbot Hostel Sydney. March 2006

WHAT 'HEALTH' CONSTRUCTS CAN BE MEASURED?

Below are some health states and constructs that show the complexity of health measurement (with examples of relevant tools in brackets). It is never possible to measure all domains that me ntal health programs may influence. We must narrow the choices of what is measured, and tools used.

DISEASE CHARACTERISTICS / PERCEPTION OF DISEASE IMPACT (worker and consumer-rated)

- Psychological distress (eg Kessler 10)
- Psychiatric symptoms / severity (eg Hamilton Rating Scale for Depression)
- Multiple aspects of symptoms and functioning (eg HoNOS, BASIS 32)

INDIVIDUAL OR ENVIRONMENTAL RISK/PROTECTIVE FACTORS FOR ONSET OR RELAPSE

- Life events and stress (eg Life Event Scale)
- Coping abilities / coping style (eg Recovery Assessment Scale)
- Behaviour / lifestyle (eg measures of drug and alcohol intake, medication compliance)
- Social adjustment (eg The Social Adjustment Scale Self Report)
- Multiple aspects: needs, recovery resources, skills (eg AVON Mental Health Measure)

GENERAL HEALTH STATUS, PSYCHOLOGICAL WELLBEING AND QUALITY OF LIFE

- Physical health and wellbeing (eg Short Form 20 Health Survey, COOP)
- Psychological wellbeing (eg The General Health Questionnaire)
- Quality of Life (eg The WHO Quality of Life Scale)

PHYSICAL & PSYCHOLOGICAL DISABILITY AND HANDICAP

- Physical disability (eg Activities of Daily Living Scales)
- Broader Impairment / Disability / Functioning (eg Life Skills Profile, Global Assessment of Functioning).

NEEDS, NEED SATISFACTION, SATISFACTION WITH SERVICES

- Satisfaction with mental health services is currently being piloted using the COPES tool
- Needs (eg CAN, CANSAS, Forensic CAN, AVON Mental Health Measure)
- Recovery measures are rapidly developing covering service satisfaction, recovery philosophy of services and individual recovery (not all are individual outcome measures)

We suggest NGOs have a minimal approach with a focus on

❶ needs assessment (CAN, CANSAS or FORENSIC CAN)

and in time, to supplement this with

❷ a measure of multiple domains of disability, impairment

❸ a measure of functioning and quality of life.

(Discussion through site visits, expert collaboration, consumer consultation and a reference group will follow this paper)

OVERVIEW OF DISCUSSION PAPER

Aim

This paper considers the *routine* monitoring by NGOs of the mental health status, risk factors, functioning and the quality of life for adult consumers when they use services (or 'routine consumer health outcome measurement' (RCOM)). It asks three key questions:

a) could RCOM contribute to consumers and workers working better together to meet consumer needs;
b) longer term, could RCOM foster the improved design and quality of NGO mental health services in NSW; and
c) should NGOs apply *a system* of *agreed* routine outcome measurement as part of a sector-wide quality improvement and service development initiative?

It was not our aim to critically appraise (scientifically) the psychometric properties of available health outcome measures. But we do qualitatively appraise the merits of selected recommended measures for potential NGO application based on the utility of measures as described by researchers who have reviewed them in published studies. We looked for the application of selected measures in a) community psychiatric rehabilitation settings and b) NGOs specifically. We make suggestions about tools that have seeming utility and provide some guidance for the initial selection of measures by NGOs (see 'Resources'). Ultimately, we concluded that **enough is known for us to suggest NGOs adopt at least the CAN /CANSAS in NSW** (*where those NGOs have structured individualised programs).

Method

Our method included a membership survey, policy review, literature reviewing, a review of unpublished and NGO literature and limited expert consultation. MHCC commenced this project after member discussion in a well-attended one-day forum in July 2005. A systematic review of international literature on psychosocial rehabilitation, which was undertaken for a separate MHCC project, also informed this paper (Penrose-Wall & Bateman 2006).

Key definitions

Routine consumer outcome measurement (RCOM) has been applied in various settings in Australian mental health systems over the past 5 years or longer including by NGOs in Victoria. The Australian Health Ministers' Advisory Council **adopted a definition** of consumer outcomes in 1992 as 'the effect on a patient's health status that is attributable to an intervention' (Andrews et al 1994:12). Measuring outcomes involves the assessment of change

in the person's symptoms or life quality or other domain, or group change and the change must be attributable to an intervention (Stedman et al 1997). Some are administered by workers, others can be done by consumers. RCOM is where repeat measures of consumer outcome are taken as part of the routine of the organisation and when staff and consumers aim to manage or impact the disease, disability or risk factors or meet the needs consumers have identified. RCOM's purpose is to approach client need systematically and to facilitate decision-making (Stedman et al 1997). The shaded boxes below are when RCOM tools might be administered (depending on what precise outcomes are being monitored).

Figure 2: 'Routine Consumer Outcome Measurement' RCOM

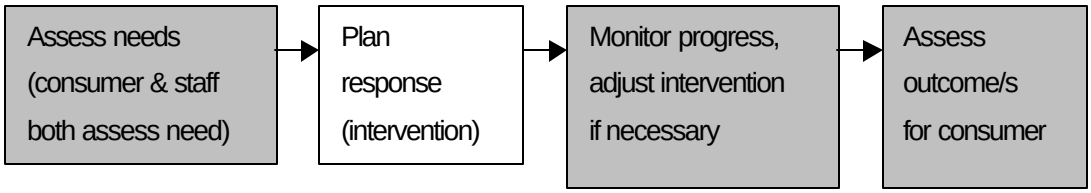
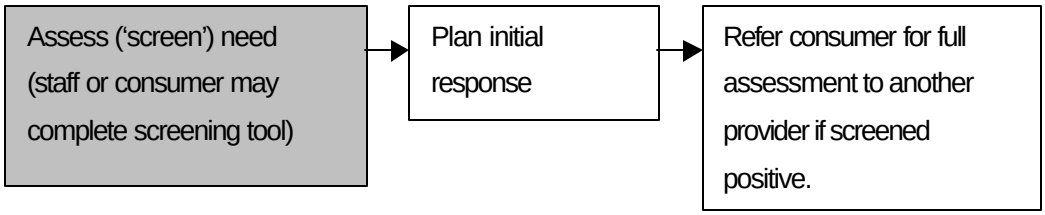


Figure 3: 'Screening'



This is in contrast to other forms of program evaluation, for example, using the same outcome measurement tools for the purpose of research or for a one-off evaluation. It is also different to using the same outcome measurement tools or 'assessment scales' for 'screening'. It is worthwhile delineating the distinction with screening now.

Findings

Our literature review found no published NSW NGO research on the science of outcome measurement. However, a decade of experience from NGOs internationally is available, principally where NGOs have developed or have participated in developing measures. Little guidance is available from the clinical and quality management literature about applying systems for outcome monitoring in NGOs (specifically) in mental health: the outcome literature on psychosocial rehabilitation programs internationally was hard to interpret since the legal entity of the host organisations of programs is often not stated. Expertise will need to be obtained from across sectors to advance NGO outcome measurement (tailored / field tested to NGO needs) however some knowledge can be applied from the use of RCOM in the public mental health services. Key findings will now be summarised.

Do consumers find outcome measurement acceptable?

The literature review reports mixed findings: consumer participation in completing outcome tools varies according to staff agreement with outcome measurement (since staff must offer the tools to consumers to use). Completion by consumers of self-rated outcome tools has been disappointing in some public mental health services yet high completion by consumers has been reported in Victorian NGOs. The early (Andrews et al 1994; Stedman et al 1997) National Mental Health Strategy consumer consultations in Australia reported routine outcome measurement is **acceptable to many consumers.** Further, in research, outcome measurement has enjoyed the cooperation of adult and adolescent consumers with mental disorders. Suicidal young people (who are high need consumers with service engagement problems) participated well in completing outcome measurement under the National Youth Suicide Prevention Strategy, including in projects by NGOs (Mitchell, 2000). In General Practice RCOM has been acceptable, including to consumers from non-English speaking cultures, such that now around 10% of GPs are inviting consumers to use outcome measures under the Better Outcomes in Mental Health program. Furthermore, RCOM has been thought of as synonymous with consumer empowerment and participation by some authors and some consumer advocates. Some place it as central to service reform as a tool to shape services to better respond to consumers' needs. However, some of these consultations were up to ten years ago. There is now need to contextualise consumer views to the present needs and to re-ask consumers if they wish NGOs to also offer them outcome measurement. This is especially important given that consumers are now experienced in outcome use in other health care systems.

Views of NSW NGOs

At least 27 organisations from a non-representative survey sample of MHCC members (27 of 33 responding NGOs) use formal self-developed needs assessments when consumers first attend their agencies and only 9 use one such tool. Approximately **3.4% (5) of MHCC member organisations and 5% of direct service-providing NGOs in NSW** are already experienced in using validated outcome measures routinely. These are large NGOs, some being involved with the Housing And Support Initiative (HASI) which applies RCOM as part of formal evaluation. Of the sample NGOs using any outcome evaluation, 15 (48%) were dissatisfied with or were reviewing their current outcome measurement for a better fit with quality improvement effort in their agencies. This shows developing evaluation skill, genuine evaluation capacity development and the use of outcome measures judiciously. We need to know more precisely what tools are in use by non respondents to be fully informed of current practices, views and needs. From earlier MHCC surveys (Bateman & Johnson 2000) we estimate that RCOM may at first be applicable to about 21% of **programs** (not organisations) within NSW NGOs: those that are currently a) structured, and b) target individuals (rather than populations). Many are large programs and RCOM would provide vital information of public

health interest and importance. These programs include supported residential, open and supported employment, centre-based and Clubhouse programs, and outreach services.

Justification – why measure outcomes for consumers?

There is consensus that much unmet need remains amongst people with mental disorders. There remains some dissatisfaction with services and services remain poorly integrated in NSW and elsewhere (Commonwealth of Australia 2006; NSW Attorney General 2005). The purpose of RCOM at the individual consumer level is to inform a worker and consumer about the consumer's needs and the consumer's progress while using programs. It is a structured mechanism built into the helping relationship to elicit specific information about functioning, symptoms or risks from the consumer that may otherwise get left out of an interview. When informed by outcome measurement, the work the consumer and worker do together may be modified if the consumer is not progressing as expected.

Shifting to the **organisational level**, we now know from Australian experience that when outcome data is aggregated for all consumers using a program, service providers can detect service and program design problems. The agency may offer the wrong programs, or programs may not be delivered at the right intensity to achieve an expected outcome and so on. Thus RCOM is a potential service development input (see Chapter 5).

NGOs often assist people with chronic and long-standing disability. Sometimes consumers do not improve in functioning and some may not be expected to improve. However, preserving consumers' level of functioning, life quality and satisfaction as they age may be shown by the outcome data. RCOM may alert program providers to at least minimal consumer health status and change or stability over time and where the program is insufficient in its design to meet their needs. RCOM thus provides one program evaluation infrastructure for NGOs.

Mandated or voluntary?

Literature suggests that **mandated systems** of outcome measurement in mental health do not always achieve genuine staff evaluation of their practice with consumers: mandated outcome measurement can be resented by workers and can yield superficial compliance with 'paperwork' or 'data entry' rather than being understood as a tool for the ongoing evaluation of practice. To obtain true evaluation benefits from outcome measurement, introduction must be skilled, well resourced and have effective and sustained leadership to support it (Pirkis et al 2005).

We concluded that the values of NGOs around **cultures of voluntarism**, non-coercion, consensus building, innovation, participation of and leadership from consumers, or in other words, organisations deciding for themselves to adopt relevant evaluation processes, is how best to approach consumer outcome measurement within NGOs. It should be offered, not

imposed. This is especially because of the complex and multiple quality frameworks organisations are currently obliged to use to secure funding and the burdensome mechanisms of reporting they face. RCOM must find a fit with the latter if it is to have value. Incentives may also play a role. Detailed workforce information is also required to appraise the training needs that NGO staff and managers will have if they are to apply RCOM.

Is there evidence that RCOM helps consumers and does it improve services?

The degree to which consumer outcome measurement **in fact works to improve service quality** in mental health is not yet well reported. One systematic review is available. Studies report it to improve the worker-consumer communication and understanding of need from consumers' perspectives. But we don't yet know with confidence if once outcome data is available to an organisation or to a system of organisations, if population outcomes improve for the group of consumers being assisted. Few studies have asked if the organisation or worker will use the outcome data to respond to what the data signals to them as needing to improve in their program. Outcome measurement in Victoria however is widely discussed in NGO conferences and forums in a way that suggests that there is active engagement in outcome measurement and service reform in response, rather than mere 'compliance'. VICSERV's submission to the Senate Select Committee on Mental Health (Commonwealth of Australia, 2006) advocates outcome measurement in NGOs.

Is consumer outcome measurement essential or optional to quality management?

Literature suggests that consumer outcome measurement in some form is an **essential tool** for quality improvement but to collect it routinely, rather than from time-to-time in ad hoc evaluations of practice or for research, is the issue. *Routine* collection is an 'ideal'. It is the only reliable way to see if programs achieve what they set out to do over time (in the real world). Outcome data collected for research purposes on the other hand has different value: it can explore deeper issues but often only at only one point in time. Research projects may achieve change-agent results and learning within organisations but only during the life of or shortly after research projects. By contrast, RCOM provides ongoing data for use in quality improvement programs year-through and has likely impacts on the cultures of organisations.

In addition to RCOM, NGOs require measures of **processes of care** that account for how the organisation performs, rather than how the consumer changes over time. Who the organisation assists and activities it undertakes and how it undertakes these activities are examples. Processes of care information is the most relevant data for quality improvement of systems of care and must be considered further to RCOM. A 'minimum data set' of agreed performance indicators (of processes of care) has been underway for Victorian mental health NGOs since 1997. Victorian Human Services manage the data collection and reporting for NGOs. The routine outcome measurement system is state-wide for NGOs and supplements this. The relative importance of consumer health outcome measurement (how the consumer is faring) vs

process measurement (how services are performing) for service planning and sector capacity building is not reported by Victorian reviews. It is still to be fully understood in the wider literature. However, quality literature supports both as needed not one or the other.

Is there justification for a state-wide RCOM system for data management / reporting?

This paper takes the perspective of NGOs as a distinct 'setting' for health care and supported 'self-care' within the wider mental health service system. Logically, NGOs must have all available tools to assist them to proactively design their part in the correct configuration of mental health services. With distinct cultures and workforces, and independent status, NGOs provide components of care that are different to public or private mental health care (Penrose-Wall & Bateman 2006). Notwithstanding that local service planning can be and should be collaborative with private and Area Mental Health Services, quality improvement for NGOs and capacity building for NGOs can be fostered at a state-wide level. This paper found through expert consultation that managing an industry-specific outcome data system may be efficient and beneficial for NGOs as critical to capacity building for the sector. This is given its overlapping yet distinct-enough roles and functions from other service systems. It would also seed a research and development infrastructure for NGOs so they may better understand their clients and communities. MHCC coordination of any state-wide agreement to pool data, quality manage the collection for NGOs and manage reporting from routine outcome data back to the sector is proposed here. We recommend that MHCC separately cost all aspects of implementing and providing governance for a system of RCOM and explore member agreement with such a concept.

'Case mix':

'Case mix' is a term generally not used by NGOs because it captures 'caseness' (of one using a 'health service'), rather than broader concepts of community membership of persons participating in NGOs. Care must be taken so that NGOs adopt relevant conceptual frameworks for outcome monitoring, not all of which can be automatically applied from how RCOM is used in the public health system. Yet case mix in the sense that it refers to 'who uses which services' and in terms of care need and complexity is vital in RCOM. Little is currently known about consumers using NGO services. Case mix must be taken into account when interpreting outcome data especially if comparisons between services or care settings are to be made. A system of RCOM would establish this information.

Is RCOM sufficient for quality improvement?

RCOM data would likely make a very important contribution to NGO knowledge development about how best to help consumers and help consumers help themselves. Given that the little data that are currently collected by NGOs are not pooled nor used to publish outcome studies in NGOs (Penrose-Wall & Bateman 2006) RCOM makes a good start to better understand NGO mental health work. However, outcome research suggests that RCOM will not replace

the need for industry-based (ie NGO-commissioned and conducted) research, evaluation and development (RED). Without NGO-specific research and development undertaken strategically and in addition to RCOM, NGOs may not be able to make the best sense of RCOM information for future program development. While a system for RCOM in an organisation will register which consumers are using their programs, more analysis of these data and further data are needed. For example, how does NGO care form part of the care pathway for consumers and what aspects of case mix will need to be thoroughly understood before comparisons between programs can be made? NGOs will need to define their programs at the level of discrete interventions. They also need to know how their program or the consumers they serve differ from others using public mental health programs, what aspects of the program accounted for the improvement and if the improvement can be attributed to the NGO program at all. NGOs also need to know more about the skills base and attitudes of their workforce and if outcome measures are being appropriately administered. Understanding consumer self care and organisational milieu and not just the components of interventions may be necessary to understanding what it is about NGOs that is responsible for achieving consumer outcomes. Finally, partnerships need to be evaluated from the perspective of NGOs as partners to test if partnerships improve the intensity and reliability of program delivery. These are more appropriately answered by research or strategic evaluations rather than RCOM. RCOM provides an infrastructure of potential use for research purposes.

Conclusion

We concluded from Australian and NSW NGO experience that outcome measurement is relevant for developing learning organisations if ground-up in its development and with consumer partnership being central to its use. That some NGOs are using outcome measurement suggests that may be receptive to adopting outcome measurement voluntarily. This may be enhanced were incentives and resources available to assist NGOs.

We concluded that MHCC is well placed to facilitate coordination of the developmental work required to assist the sector with outcome measurement with a leadership team of members and NSW Health's input to work through implementation support issues.

Finally, NGOs have much to contribute to knowledge in the mental health field. Industry-based RED in addition to a system of RCOM is required. Nonetheless, RCOM is a feasible place to start contributing to the knowledge base about community mental health and how it is advanced through community organisations.

RECOMMENDATIONS

Recommendation 1: Better understand the NGO workforce:

MHCC's current Training and Workforce Development initiatives are relevant to informing how best to support NGO staff to operationalise RCOM and to sustain support mechanisms for RCOM.

Recommendation 2: For NGOs to access the knowledge base:

That NSW Health provides access to the electronic library, CIAP, to NGOs that identify as providers of mental health programs.

Recommendation 3: Introduce RCOM in the context of EBP:

That MHCC's Workforce Development Program include an explicit "Evidence-based practice module" to take into account the need to deeply understand EBP principles along with the application of any tools such as guidelines, use of literature, program design and not just outcome measures. This will lead eventually to service redesign and not just 'quality improvement' where the former is needed.

Recommendation 4: Foster outcomes leadership capacity building:

That MHCC seed a small Evidence-based practice SIG similar to the Special Interest Groups of the College of Psychiatry, Australian Association of Social Work, College of Nursing and the APS.

The SIG would be an electronic network of NGO researchers, consumers and practitioners tasked with disseminating through MHCC website or newsletter a) short appraisals of new primary research as it becomes available and b) summary implications of commissioned research from Commonwealth Strategies and clearinghouses and c) implications from recovery research on 'recovery outcome measurement'. The ***focus of the SIG work*** *would be limited to summarising systematic reviews, RCTs and experimental research on resilience, recovery and rehabilitation outcomes relevant to NGO care models.*

The SIG would assist MHCC's communication strategies on outcome monitoring by keeping a watching brief and updating 'Reference Manager' or a similar research database on research in psychosocial rehabilitation so that relevant research retrieved can be easily re-accessed and communicated.

Recommendation 5: Scope RED capacity building models:

That MHCC explore models of research evaluation and development (RED) capacity building for the sector in addition to outcome monitoring and streamlined QI processes.

Recommendation 6: Cost outcome monitoring State-wide:

That MHCC commission a short feasibility study to cost (and opportunity cost) the introduction of consumer outcome measurement in NGOs, informed by Victorian PRDSS system establishment and other examples. This would take account of work underway on the design and purchase of information systems for use by NGOs and MHCC for organizational and aggregated data collection and reporting.

Recommendation 7: Seed quality systems of parity with other sectors for outcome collection programs to be developed by NGOs:

That NSW Health fund a ***small grants incentive pool*** *to enable NGOs to select outcome measures relevant to NGO consumers' needs during 2007/8. These infrastructure incentive grants should fund NGOs to host strategic and evaluation planning processes and prepare a business case for which outcome measures they prefer to adopt and why. This would follow a Technical Paper by MHCC providing more simplified guidance to NGOs on 'recommended' measures. Grants up to $15,000 are proposed subject to organizational size. The output would be registered organisational commitment to a program of RCOM.*

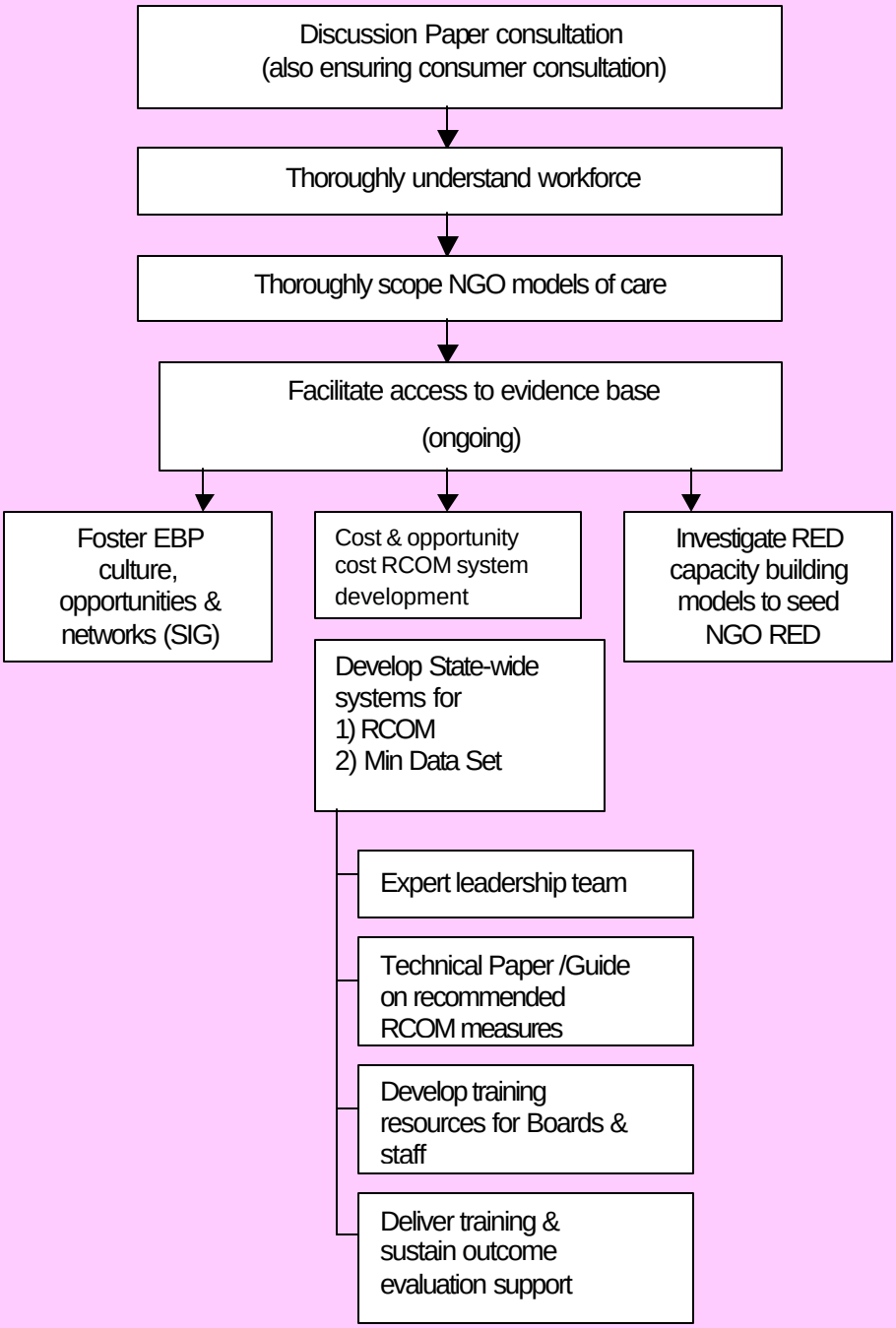
Recommendation 8: Implement State-wide coordination of RCOM in NGOs and
Recommendation 9: Develop State-wide minimum data set

Recommendation 8 and 9 require NSW Health financing of an MHCC outcome coordination unit. Such a unit would coordinate two information systems: one program would develop with members a minimum data set of agreed indicators of processes of care that define quality NGO mental health services so basic demographic information on service users and their pathways through NGO services could be collected continuously.

The second information system would monitor at the State-level, health outcomes for de-identified service users reported to the Unit by MHCC participating organisations.

The output would be aggregated outcome monitoring and reporting to the sector, technical support to members, processes for showcasing evaluation capacity building and processes to assist organisations work with or along side MHOAT data collection processes so that both inform service development and planning.

Minimum strategic steps for MHCC within these recommendations



SOME VIEWS ON OUTCOME MEASUREMENT

'(that) Mental health NGOs research and field test suitable outcome measures for the various types of services provided by the mental health NGO sector. Common outcome measures would provide some consistency across the state and allow for the collation of data on a wide scale if required'.

Bateman & Johnson (2000) MHCC MAPS Project

"Outcome measurement is not the main game…

Helping people is the main game. It requires relationship, acknowledging the person as a person without which there is seldom health gain.

Outcome measurement will only add value if it is not applied to exclude people from services nor to constrain NGOs in developing new forms of services. If used well, it may help them develop new forms of services".

Emeritis Professor Ian Webster AO, Chair National Advisory Council on Suicide Prevention, Physician, Matthew Talbot Hostel Sydney. March 2006

"Non government organisations contribute to a range of interventions…there is a need for further classification and evaluation so that the particular contributions of this sector can be recognised. These organisations may also be mental health specific or generlc".

Professor Beverly Raphael, *A Population Health Model for the Provision of Mental Health Care* (2000) p26.

'The RANZCP supports the routine collection of outcome data. However, the results need to be given to services in a timely and useful form….It is essential that routine data collection can be done efficiently and that it does not become so excessive that it interferes'.

Royal Australian and New Zealand College of Psychiatrists Submission to the Senate Select Committee on Mental Health 2005.p.10.

"There is a drastic need for funding at various levels to appropriately examine the processes and outcomes of Australian psychosocial rehabilitation approaches (including) research into outcome measures for community based rehabilitation services".

VICSERV Submission to Senate Select Committee on Mental Health. p. 27. May 18, 2005.

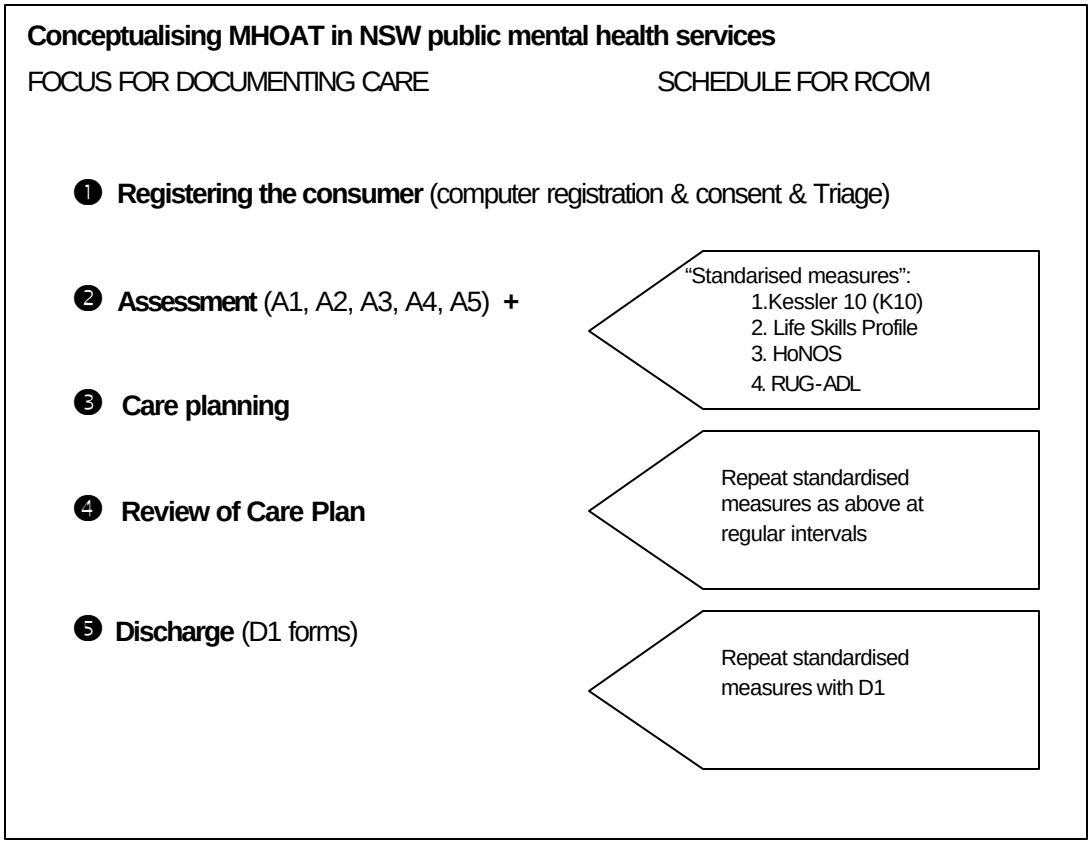
ALSO SEE CHAPTER 3 SURVEY OF NGOs VIEWS AFTER USING RCOM

OUTCOME MEASUREMENT AND THE HELPING RELATIONSHIP - EXAMPLES

MHOAT in NSW public mental health services

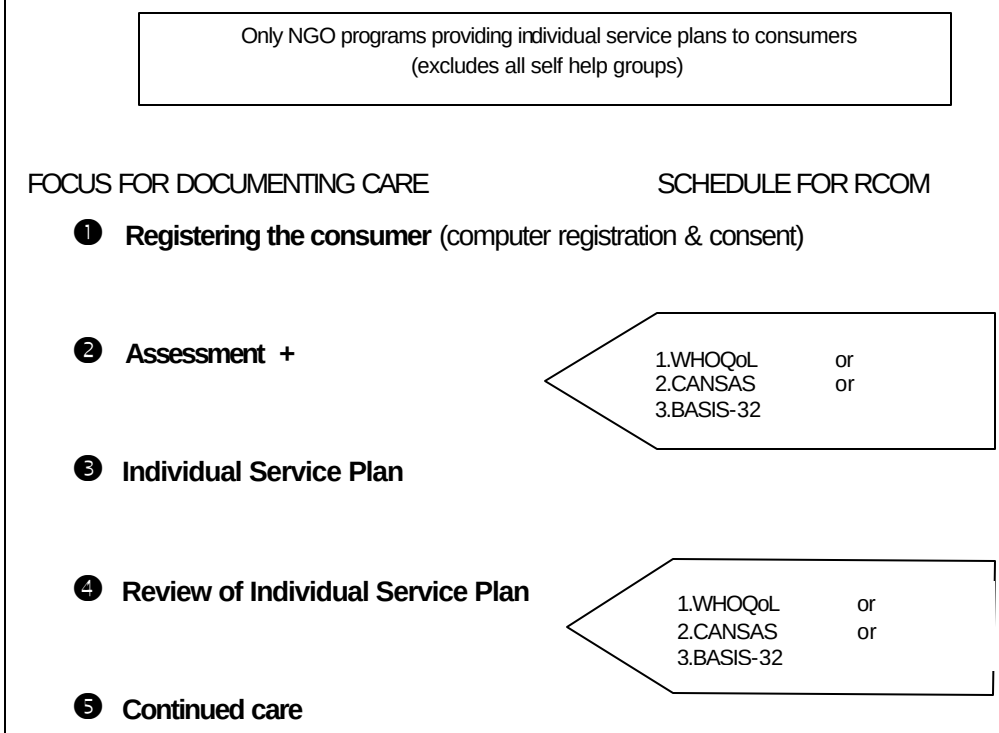
In 2001, NSW Health mandated the use of the system, Mental Health Outcomes and Assessment Training (MHOAT), for all public mental health services. MHOAT is not a tool or a single outcome measure. It is a standardised way of documenting *the summary of all* clinical care provided to a consumer for their mental health. It aimed to standardise and train staff to perform more comprehensive clinical assessments. MOHAT is comprised of a suite of clinical tasks called, 'modules' to be performed using paper-based forms and electronic formats in some teams which are then filed in the client's medical record. Within MHOAT are three 'standardised measures' (the routine consumer outcome measures), which are done at entry, review and exit (discharge) from the mental health service.

Conceptualising MHOAT in NSW public mental health services



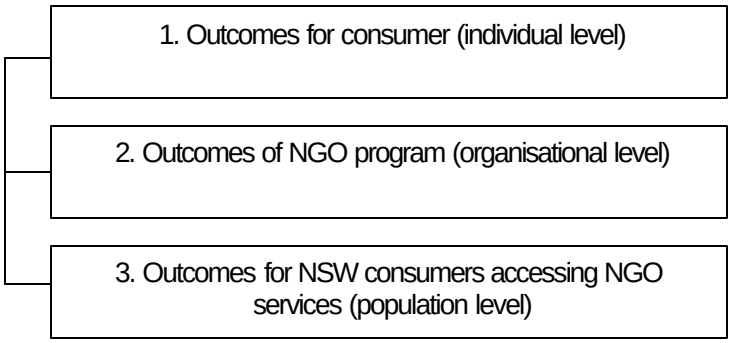
Below is an illustration of how outcome measurement works in Victorian NGOs within the Psychiatric Disability Rehabilitation and Support (PDRSS) services. The PDRSS services collect the 32-item Behaviour and Symptom Identification Scale (BASIS-32) (McLean Hospital), the WHOQoL (World Health Organisation Quality of Life Scale) and the CANSAS – the short version of the Camberwell Assessment of Need (refer Appendices). This only applies to programs where consumers have an Individual Service Plan. For example, self-help groups do not participate.

Figure 11: RCOM in Victorian PRDSS (VICSERV) mental health services



Levels of data analysis after collecting consumer health outcomes

RCOM is hypothesised to improve care outcomes at the following levels.



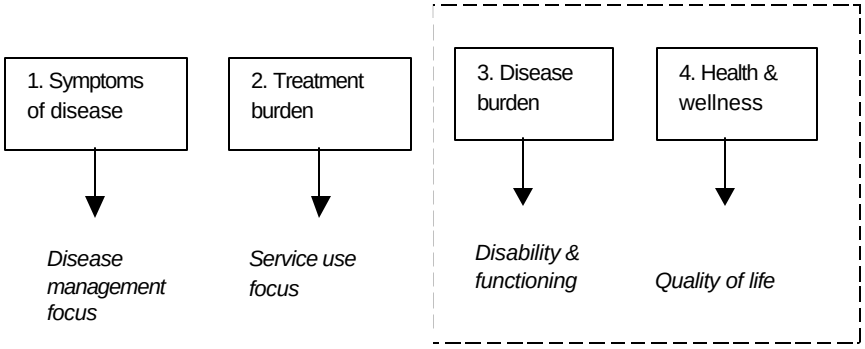
SOME CHOICES OF OUTCOME MEASURES

Tool	Time	Used by NGOs	Used by MHOAT	Description
Global Assessment Scale (GAS)		✓	✗	Developed in USA in the 1970's, the GAS measures overall severity of psychiatric disturbance.
Global Assessment of Functioning (GAF)		✓	✓	The GAF (revised from the GAS) is a clinician-completed rating of overall functioning on admission. It is used for treatment planning, measuring treatment impact, and predicting outcome. It is used only with respect to psychological, social and occupational functioning. At least one NGO uses this measure. They reported little change across time with this measure. Nonetheless a measure of disability / functioning helps NGOs to plan and understand their service population. In the MAP Project, MHCC used the SF12 for a base line measure of disability of a consumer as against their 'needs', the latter detected by the CAN. The GAF is being proposed within HASI funded NGOs..
Kessler 10 (K10) Symptom Scale	**5 min**	✓	✓	A brief consumer-completed 10-item questionnaire, designed to survey psychological non-specific distress in the anxiety- depression spectrum. It not as useful in the measurement of distress in other disorders such as psychosis. Validated for primary care. Used extensively in Australian general practice under BOMH and in Australian research. Thus, comparison data exists for Australian conditions. It uses 10 questions with 5 response categories. An example of such questions is *'In the past 4 weeks, about how often did you feel hopeless?'* The response categories are: none/a little/some/most/all of the time. Divisions of General Practice are NGOs using the K10.
Health of the Nation Outcome Scales (HONOS) *Wing et al (1994) Health of the National Outcome Scale. Royal College of Psychiatrists London.*	**15-30**	✓	✓	This scale was developed in the UK, and is a clinical tool completed by the clinician to measure consumer outcomes in behaviour, symptoms, impairment and social domains. Some members of MHCC familiar with it have found it hard to use that it is hard to use, and not a diagnostic tool. . At least 2 NGOs uses HONOS, as required to by the Area Health Services, in fulfilment of funding agreements. HONOS is not felt to be useful by one of these NGOs, in the context of their services.

Life Skills Profile (LSP). *Rosen A, Hadzi - Pavlovic D & Parker G (1989). The Life Skills Profile: a measure assessing function and disability in schizophrenia. Schizophrenia Bulletin; 15:325-337.*		✓	✓	Worker-completed, developed in Sydney. It was developed specifically to measure the functional skills of people with schizophrenia. It is a rating scale designed to assess general functioning, and abilities in basic life skills in past 3 months. Includes self-care, non-turbulence, social contact, communication and responsibility, and is designed to pick up changes. The most commonly use version is LSP-16. A longer version is the LSP 39 and more recently the LSP-20 has been developed. It has standardisation data on Australian populations and good reliability. At least one NGO uses LSP, where required to by the Area Health Service in fulfilment of a funding agreement, but does not find it of value. A number of clinicians using it also find it insensitive to changes in the consumer's capacity to operate in the world. However some services find it useful and one large NGO is considering using the longer version of the LSP.
Behaviour and Symptom Identification Scale (BASIS 32). *Eisen et al (1999). Assessing behavioural health outcomes in outpatient programs: reliability and validity of the BASIS-32. J Behavioural Health Services & Research 26(1).5-17.*	**15-30**	✓	✗	Developed in USA, BASIS 32 is a Consumer Self Rated Tool, designed to asses the consumer's own perception of his/her mental health, and covering major symptoms and functioning difficulties. The 32 items relate to: relation to self and others, daily living and role functioning, depression and anxiety, impulsive and addictive behaviour, and psychosis. Questions such as 'In the past week how much difficulty have you been having in the area of: eg Household responsibilities; social and leisure activities, are posed, with responses requested in the range No Difficulty, to Extreme Difficulty. BASIS 32 is used extensively in the USA and also by NGOs in Victoria. In NSW it is used by Neami and is being tested by other NGOs. Organisations using this tool regarded it as valuable.
Camberwell Assessment of Need (CAN). *Phelan et al (1995). The Camberwell Assessment of Need: the validity and reliability of an instrument to assess needs of people with severe mental illness. Br J Psychiatry 167: 589-595.*	**20 min**	✓	✗	This is a worker and consumer joint assessment tool developed in UK. The adult CAN is a family of questionnaires for assessing the wide range of problems that can be experienced by those with severe mental disorders in 22 areas of life. It also assesses perceptions of needs by worker and/or carer. 3 summary variables matter most: total number needs, total number met, total number unmet. Studies indicate unmet need is most promising to investigate since it best predicts quality of life (UK 700 Group, 1999). Staff and consumers will each measure need differently.

Camberwell Assessment of Need Short Appraisal Scheme (CANSAS	**10 min**	✓	✗	A one-page assessment which summarises whether a person with mental health problems has difficulties in 22 different areas of life, and whether they are currently receiving any effective help with these difficulties. CANSAS is designed for routine clinical work or as an outcome measure in research studies. Questions such as 'Are you able to look after your home?; Have you recently felt very sad or low?' are included. Tick boxes are offered for a choice of 4 responses, which include 'This area remains a serious problem for me despite any help I am given (unmet need); to: 'I do not want to answer this question.' This tool is used by some NGOs who find it valuable in informing the clinical process and making a care plan which fits the individuals' needs. It is also used in the Collaborative Goal Technology model.
Recovery Assessment Scale		✓	✗	Developed in the USA as a way of assessing Recovery, which is defined as persons with severe mental illness living a satisfying life. The RAS tests for empowerment, coping ability, and quality of life. It is a 41-item survey, (which can be reduced to 24) rated on a 5-point scale, from Strongly Disagree, to Strongly Agree. Items include: 'I can handle it if I get sick again; There are things that I can do that help me deal with unwanted symptoms'. The RAS is one of several Recovery oriented measures. Not used consistently in NSW, but known by several NGOs.
Avon Mental Health Measure (AMHM). **MIND UK (2001)**	**20 min**	✓	✗	Developed in 1996 and tested over 3 years by MIND UK (Mental Health Association) through MIND and Bristol University and United Bristol Health Care NHS Trust. Workshopped with consumers, GPs, social workers and voluntary sector workers to develop the tool covering 25 aspects of need: housing, self care, effects of medication, social support, routine, discrimination, community involvement, risk to self, anger, substance misuse, mood swings, symptoms, income, communication skills and opportunities, money management, sleep disturbance. Includes crisis and relapse plan. It helps people plan to move away from discriminatory stereotypes. In 2005 it became endorsed for use in RCOM by the NHS nationally in Scotland for all mental health services in all sectors.

PRINCIPLES IN SELECTING OUTCOME TOOLS



There has historically emerged a crude division of labor where there is the expectation that clinical public sector services will *at minimum* detect, comprehensively assess and treat symptoms of mental disorders. To evaluate the effectiveness of clinical services RCOM tools with a focus on outcome domains 1 and 2 above would be indicated at the very least. However, clinicians cannot make treatment decisions with consumers unless they also know about functioning and the level of social support available to the consumer. This is why multi-domain measures such as HoNOS and multi-informant measures are recommended for public clinical mental health services. The focus of most NGO interventions in NSW at least, aim to address outcome domains 3 and 4 above, whether or not they additionally address the symptom and treatment domains of care. The principles we list have been introduced by other authors (Andrews et al 1994 and Stedmen and colleagues 1997) and we have modified or added to these considerations that are relevant to the NGO practice context.

PRINCIPLE 1 RELEVANT DOMAIN TO NGO ROLE	Select outcome measures that monitor the domain of outcome relevant to the role of the NGO in mental health care (consider the mission of the NGO and of its specific programs). Alternatively, use a multi-dimensional measure, (Andrews et al 1994) so long as it includes items of outcome relevant to what the NGO performs and intends to achieve.

PRINCIPLE 2 RELEVANT TO CONSUMERS	Ensure measure does not stigmatise and measure what consumers find most relevant. We are yet to consult consumers, however, Andrews et al (1994) found consumers wanted outcome monitoring using: • measures of 'disability' and 'quality of life'; • measures of 'satisfaction with service'; and • measures of 'symptoms'.

PRINCIPLE 3	Select from field-tested measures. Field-tested measures (eg in the Table above and in Stedman et al) have published the merits and deficiencies of measures for routine use in the Australian clinical or international NGO

FIELD TESTED MEASURES	context. While Australian field-testing under the National Mental Health Strategy did not include NGOs, the deficiencies of these measures are already published. VICSERV experience and NSW NGO experience with outcome measures might be considered field-testing and consultation with these NGOs can assist NGOs with their selection of measure.

PRINCIPLE 4 PROMOTE RELATIONSHIP	Select measures that are engaging to use and which stimulate understanding and engagement between the worker and consumer around the consumer's experiences, preferences and needs. Andrews et al (1994) reported the need to only use brief measures that did not burden consumers and workers or detract from the working relationship.

PRINCIPLE 5 COST & EASE	Andrews et al (1994) also reported that measures need to be: • low cost; • require minimal training to be used; and • require minimal training for administration, interpretation and scoring.

PRINCIPLE 6 AVOID DUPLICATION	Select measures consumers are not over-sensitised to (and are tired of completing – 'the coaching effect') through routine use under MHOAT. Where consumers have active care coordination by an Area Mental Health Service or a Care Plan with a GP, avoid re-collecting the same information. Ask consumers to consent to the NGO obtaining information from the other providers instead. In shared care and partnerships, agree between organisations which organisation will collect and administer RCOM. MHOAT measures do not focus on 'met and unmet needs', whereas the CAN and CANSAS do while also providing information about consumer characteristics.

PRINCIPLE 7 COST & EASE	Andrews et al (1994) also reported that measures need to be: • brief and low cost; • require minimal training to be used; and • require minimal training for administration, interpretation and scoring.

PRINCIPLE 8 DON'T RELY ON MEASURES OF SATISFACTION ALONE	Satisfaction of consumers and carers while important to quality improvement is difficult to measure with reliability. The relationship of satisfaction to components of care is complex especially in mental health care (Lessing & Beech 2004) Vulnerable groups who depend on services are found to report high satisfaction regardless of the actual quality of programs. People with mental health diagnosis have been found to report lower satisfaction with general health services than other persons (Hermann et al 1998) raising problems of interpretation of data collected for improving service quality. The Mental Health COPES project is developing measures to overcome these issues and should guide NGOs on satisfaction surveys. It is generally accepted that measures of satisfaction alone are insufficient for quality improvement purposes (Lessing & Beech 2004).

Conclusion

There is little reason to object to individual NGOs administering at least the CAN or CANSAS on a routine basis where they have individually tailored programs intending to achieve the meeting of mental health needs. One or two additional tools can be added. There are at least three key ways NGOs might become involved in routine health outcome measurement subject to consumer expectations and preferences of them:

- they might receive (share) data with consumer consent, already collected from other service providers rather than collected directly themselves;
- NGOs might collect outcome data using tools that are the same as that collected by clinical specialist mental health services (MHOAT); and/or
- NGOs might collect outcome data of a kind that is qualitatively different from that collected by clinical specialist mental health services or some overlap in tools as is the case in Victorian PDRSS sector, ensuring they collect what is directly relevant to evaluating their own program effectiveness.
- In any case, data pooling for careful analysis at the population level is an important infrastructure for future NGO program development and this could be managed for mental health NGOs by an appropriately staffed unit for this purpose within MHCC.

For References, please refer to full Discussion Paper

RESOURCES

Websites containing information on outcome measurement

Mental Health Resources: Psychiatric Rating Scales:
http://www.library.adelaide.edu.au/guide/med/menthealth/scales.html#Ghttp://www.iop.kcl.ac.uk/
Information about Camberwell Assessment of Need.

See also Victorian Human Services Outcome Measure Guidelines- version 2
www.health.vic.gov.au/mentalhealth/outcomes/pdrss

Victorian Government Health Information: Outcomes Measurement

http://www.health.vic.gov.au/mentalhealth/outcomes /concare.htm

Australian Health Outcomes Clearinghouse.

There are many reports from the National Mental Health Strategy on case mix, outcome measurement and information system development to support quality improvement and routine outcome monitoring. These date from Andrews et al (1994) onwards. Many are referenced in this Discussion Paper. Readers are referred to Commonwealth Suicide Prevention Branch and State and Territory Mental Health Branch Websites for the links to these commissioned reports.

Text books containing information on outcome measurement

IsHak WW, Burt T, Sederer LI (2002). Outcome Measurement in Psychiatry: A Critical Review American Psychiatric Publishing Inc. Washington.

There are three sections in this book. Section three covers cultural issues and workforce resistance to outcome measurement, health service organisation, training needs and innovations. 14 of 25 chapters deal with the measures themselves and their suitability for different applications in practice.

McDowell I & Newell C (1996). Measuring Health A Guide to Rating Scales and Questionnaires Second Edition. Oxford University Press. New York.

There are several editions of this large text book. It provides 10 chapters, usefully using the first 2 to conceptually overview psychometric and econometric measurement and the development of outcome measures for research and practice. The remaining chapters include an introduction to a subgroup of measures, followed by the tool themselves, followed by research status on the validity and reliability and correct application of the tools. The Chapters are called: Physical Disability and Handicap (16 scales); Social Health (13 scales), Psychological Wellbeing (10 scales), Depression (8 scales), Mental Status Testing (11 s cales), Pain Measurement (9 scales), General Health Status and Quality of Life (21 scales). Finally it provides guidance for the development of measures.

Thornicroft G, Tansella M (1996). Mental Health Outcome Measures. Springer-Verlag, Berlin.

This is a 239 page text book. It is a collection of articles about the application of outcome measures. It is not recommended for key workers but may inform leaders /managers..

NOTES