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

DISCUSSION PAPER

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Mental Health Coordinating Council of NSW

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WORKFORCE DEVELOPMENT

QUALITY AND OUTCOMES ☑

PARTNERSHIPS

quality &

outcomes

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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).

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.

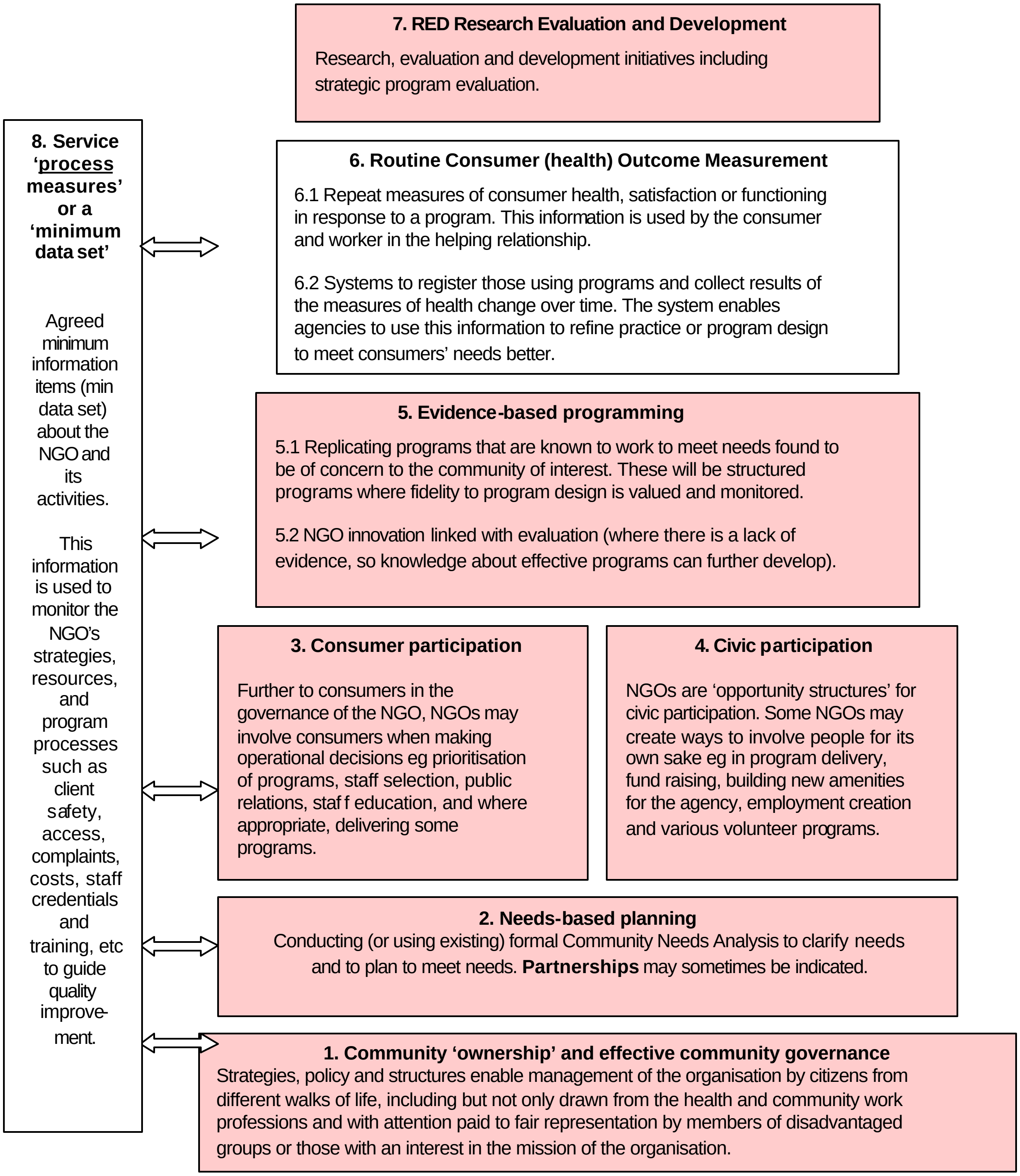
MHCC's membership includes specialist and generalist community organisations. 'Specialists' formed for the purposes of promoting mental health, preventing mental disorder or to assist those with mental illness and disability arising from the illness. 'Generalist' (or multi-purpose) agencies include other 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.

A QUALITY FRAMEWORK FOR NGOs

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



7. RED Research Evaluation and Development

Research, evaluation and development initiatives including strategic program evaluation.

6. Routine Consumer (health) Outcome Measurement

6.1 Repeat measures of consumer health, satisfaction or functioning in response to a program. This information is used by the consumer and worker in the helping relationship.

6.2 Systems to register those using programs and collect results of the measures of health change over time. The system enables agencies to use this information to refine practice or program design to meet consumers' needs better.

5. Evidence-based programming

5.1 Replicating programs that are known to work to meet needs found to be of concern to the community of interest. These will be structured programs where fidelity to program design is valued and monitored.

5.2 NGO innovation linked with evaluation (where there is a lack of evidence, so knowledge about effective programs can further develop).

3. Consumer participation

Further to consumers in the governance of the NGO, NGOs may involve consumers when making operational decisions eg prioritisation of programs, staff selection, public relations, staff education, and where appropriate, delivering some programs.

4. Civic participation

NGOs are 'opportunity structures' for civic participation. Some NGOs may create ways to involve people for its own sake eg in program delivery, fund raising, building new amenities for the agency, employment creation and various volunteer programs.

2. Needs-based planning

Conducting (or using existing) formal Community Needs Analysis to clarify needs and to plan to meet needs. **Partnerships** may sometimes be indicated.

1. Community 'ownership' and effective community governance

Strategies, policy and structures enable management of the organisation by citizens from different walks of life, including but not only drawn from the health and community work professions and with attention paid to fair representation by members of disadvantaged groups or those with an interest in the mission of the organisation.

8. Service '<u>process</u> measures' or a 'minimum data set'

Agreed minimum information items (min data set) about the NGO and its activities.

This information is used to monitor the NGO's strategies, resources, and program processes such as client safety, access, complaints, costs, staff credentials and training, etc to guide quality improvement.

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 relevant 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 mental 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)

EXECUTIVE SUMMARY

> *'(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*

> *"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.*

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).

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.

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.*

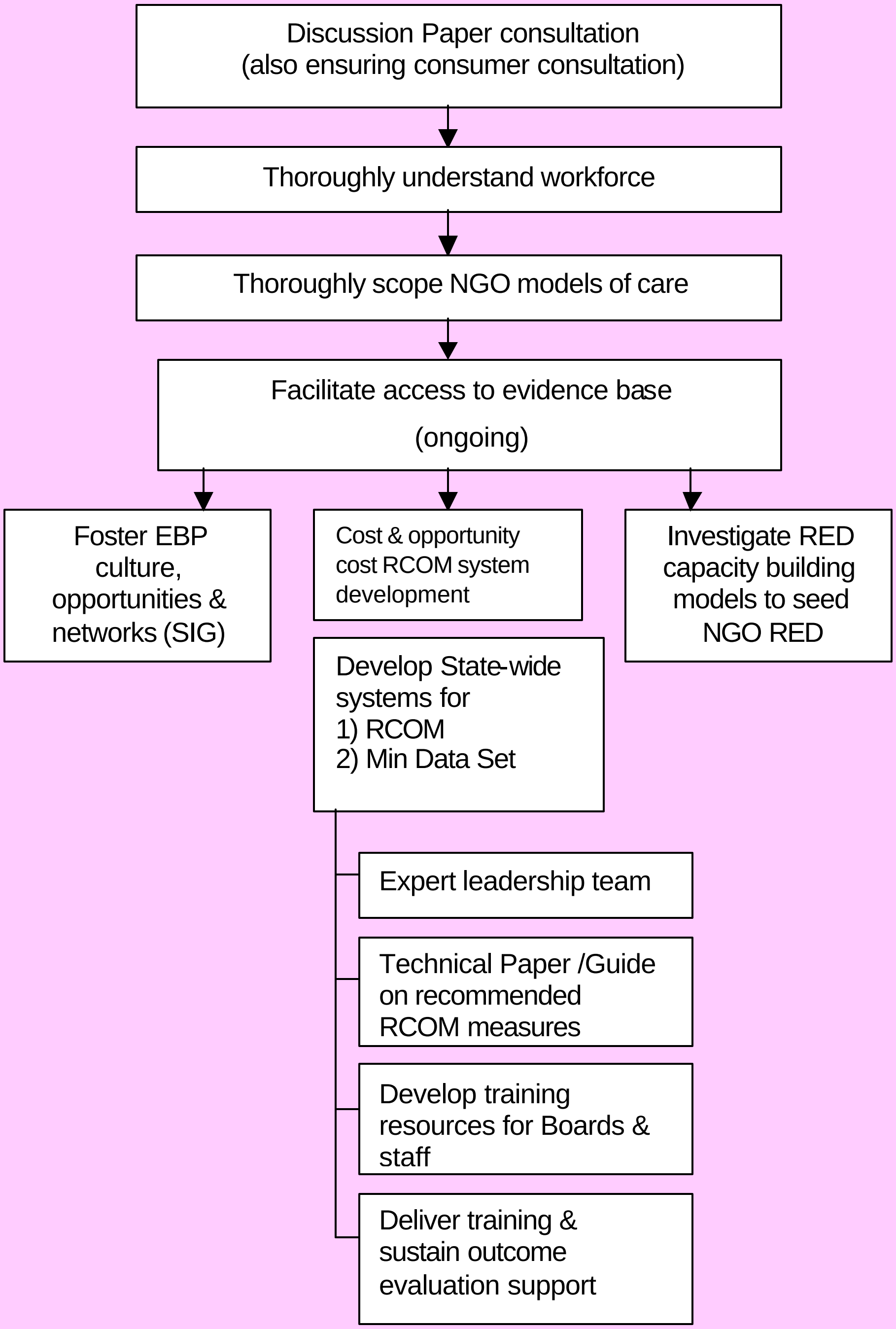
Recommendation 8: Implement State-wide coordination of RCOM in NGOs and
Recommendation 9: Develop State-wide minimum data set

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



1 INTRODUCTION

"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 further you step away from the experience of consumers, the less useful the data actually is".

Cath Roper (2005, p 25) Researcher

NGOs provide practical community programs, policy advocacy and humanitarian aid. In the health field, some NGOs provide niche programs that only a few people need while others offer programs that have much in common with the kind of essential services provided by governments. NGOs are funded by Governments for only those programs that Governments recognise as contributing to wider (recognised) public health needs. In the case of mental health, NGOs provide discrete resiliency, recovery and rehabilitation (including disability support) interventions under service agreements. We discuss: how do we tell what outcomes we generate for consumers by the discrete mental health care programs of NGOs? We conclude that NGOs in NSW could benefit by developing capacity to demonstrate these outcomes wherever possible.

Contemporary human services including schools, employment services, policing and justice services, and not just hospitals and health services, are now outcome oriented. Evidence-based policy seeks to direct funding to 'programs' that work, rather than fund 'organisations' based on historical precedent. Evidence-based programs seek to manage the outcomes of care. This has come about because consumers generally now expect more from services and taxpayers expect accountabilities for funds expended (Muir Gray 2001). Moreover, there remains considerable unmet mental health need in NSW, as elsewhere, such that we must improve the reach, coordination, effectiveness and quality of all mental health services (Commonwealth of Australia 2006).

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). As Professor Gavin Andrews (1997) notes, 'There are no outcome measures, only measures of symptoms, of disability and of risk factors, which, **when repeated**, may reveal the change due to (treatment), and thus function as outcome measures'. Later we describe how different authors have categorised different kinds of outcomes. Some are administered by workers, others can be done by consumers.

Thus, 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). RCOM is done by the worker and consumer separately or together at or soon after the consumer uses a service. 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

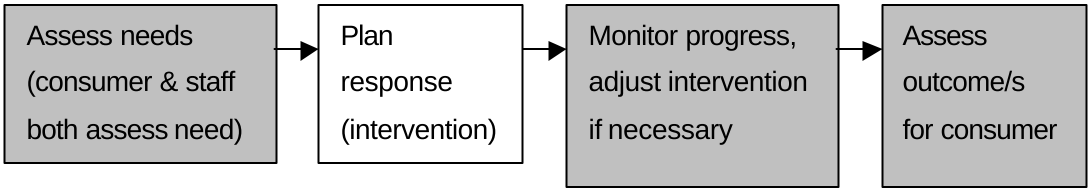
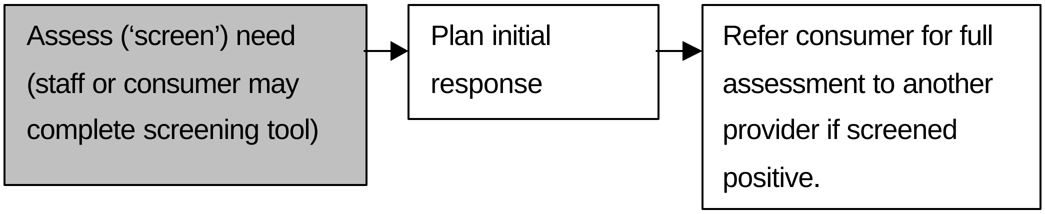


Figure 3: 'Screening'



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.

Screening can be population-wide or else it may target groups thought to be at risk of a health problem or behaviour. It is proactive, targeting 'defined groups in the population who do not necessarily perceive that they are at risk of a disease or its complications' (Muir Gray 2001:85). A test (screening tool) is offered 'to identify who is more likely to be helped than harmed by further tests or treatment to reduce the risk of disease or its complications' (Muir Gray 2001:85). Screening can also include self-screening, that is, tools used by consumers themselves either with a professional or at home.

Structured mental health screening is now commonplace in schools and general practice. The Mental Health Association of NSW Inc provides an example of NGO screening: they screened the general population for depression through attendances at community pharmacies as part of a mental health awareness program. Other NGO examples might include screening for depression among those with schizophrenia; screening people who are homeless for a current mental disorder; screening the relatives and carers of those using self help groups for undetected distress; screening for children at risk for mental health problems; and screening all those with mental disorder for suicide risk. The extent to which NGOs use structured screening and formal disability needs assessment is currently poorly understood (Chapter 3).

Scope

We address the acceptability and utility of RCOM in NGOs in adult mental health care. We also address RCOM in the context of integrated care. 'Integrated care' is where NGOs and public mental health services (or conversely, NGOs with general practice or other private providers) sometimes share the care of some clients. In integrated care each party has a focus on slightly different outcomes but have joint interest in overall outcomes for the consumer. RCOM is the focus although we acknowledge a potential role for screening by some NGOs. We touch on alternative approaches to quality improvement that are outcome-oriented and discuss the merits of each given the existing quality frameworks NGOs work within to sustain their funding. The likely choices NGOs have of field-tested RCOM tools in the Australian context are included in Chapters 3-5 but we researched the use of RCOM tools by NGOs internationally. We leave aside child and adolescent mental health outcome measurement.

Purpose

The paper's purpose is to help NGOs discuss if RCOM is relevant to their programs, and if so, to help them to chose measures with demonstrated value.

Justification

One of the reasons to propose RCOM in NGOs is that there is presently patchy understanding as to why some psychosocial rehabilitation programs in general, and why NGO-delivered psychosocial programs in particular, are effective. It may not always be clear which part of the intervention worked and at what intensity did it work. This is a recognised research deficit globally (Barton 1999) not helped by the fact that NGOs in mental health generally do not have research and development (health services research) infrastructure. While there are exceptions such a Aftercare, SANE and larger charities, NGOs are principally practice-based rather than research organisations so these research gaps are likely to go unaddressed. RCOM may assist this capacity to develop and can stimulate questions that need to be answered through evaluation and research activity.

It may also be the case that some NGOs could modernise how they plan and prioritise what they contribute. This is because many NGO programs originated years before the introduction of more effective new generation antipsychotics and the strategic environment and consumer needs are now very different to when their programs were first developed. For example, care in the community is now the norm rather than an innovation and it is insufficient just to offer 'community-based' care via NGOs unless it contributes to outcomes for consumers other than as an alternative setting to hospital care. We need to tailor programs to the course and outcomes of mental disorders to impact the problems experienced by consumers in the community and to support their strengths in the community. One group of authors claim that given the residual disability remaining for most people with schizophrenia, the priority is to get the best 'synergy' between treatment (symptom control principally through medications) and 'psychosocial rehabilitation' (Lauriello et al 2003) to optimise consumer outcomes. NGOs and public sector services face the same challenge in this regard both having responsibility to achieve this synergy.

Finally, consumer recovery philosophy demands that evidence-based programs be at least attempted. Consumers expect services to achieve more than symptom control. 'Recovery' provides an optimistic framework for all programs to move closer to meeting consumer expectations. RCOM facilitates precise and systematic scrutiny of consumer needs and status over time. For all these reasons, the questions this paper answers are: might routine consumer outcome measurement

a) contribute to consumers and workers working better together to meet consumer needs (consumer level); and
b) help to improve the design of NGO programs and to manage the quality of NGO mental health services in NSW (organisational level); and
c) should NGOs apply *a system* of *agreed* routine consumer mental health outcome measurement as part of their quality improvement and service development frameworks? That is, would it be worthwhile to agree on at least some common outcome measures to be used by NGOs, and for the outcome data collected by individual NGOs to be pooled for aggregated analysis? Would this information inform planning any better say, than occasional census surveys? How important is outcome measurement for planning for the NGO sector?

Perspective

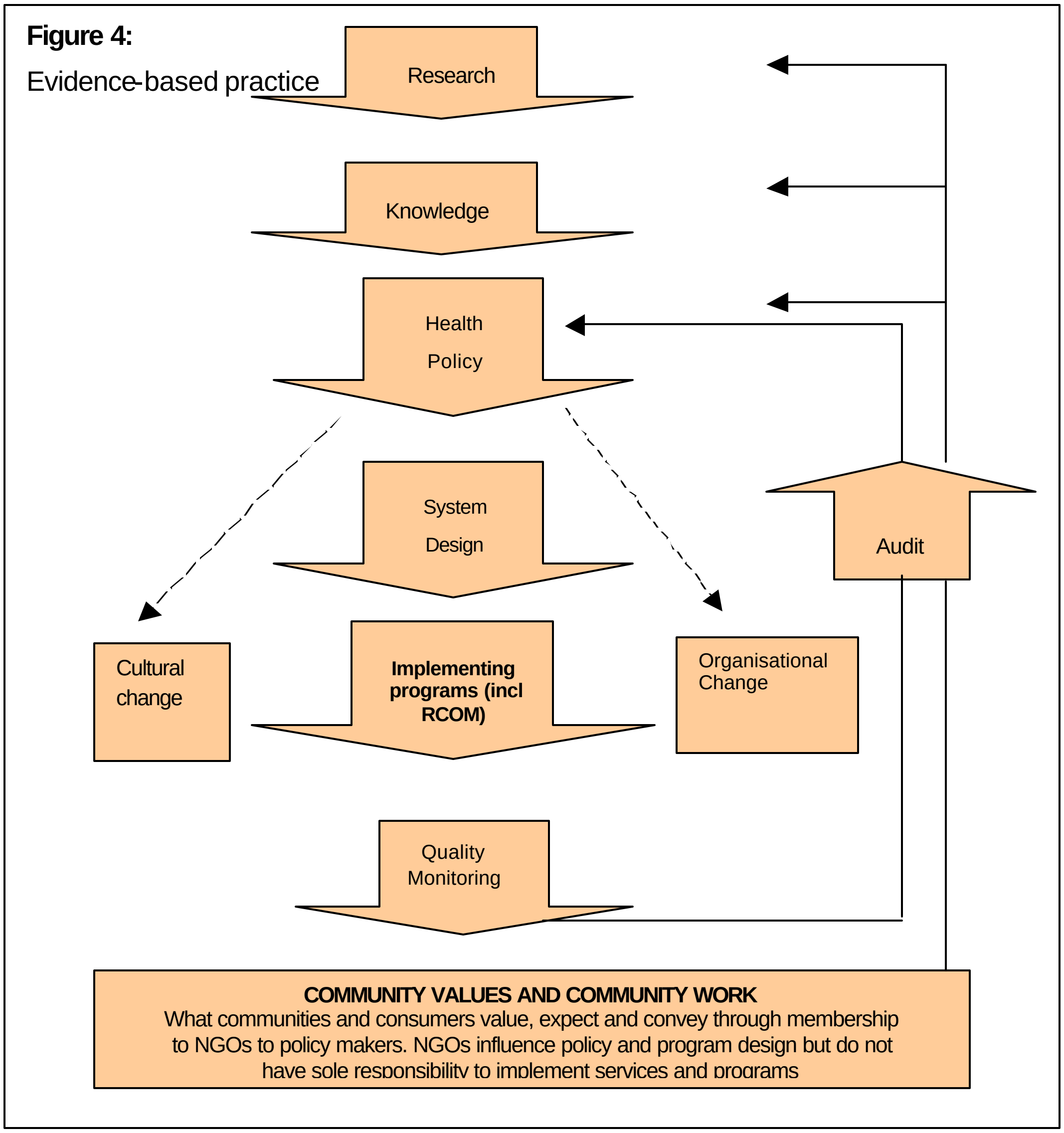
In Chapter 2 we shift from a perspective of NGOs based on who they are (as socio political and socio cultural entities with a distinct value in democratic societies) and we focus on what they do to assist people with mental health needs (an intervention approach as shown in Figure 4). Both perspectives remain important and operate at different levels. The intervention approach puts the consumer at the centre rather than the organisation. This is not to say that organisational characteristics are not important. They may mediate the achievement of health outcomes, an explanation that has been put for why self help groups and Clubhouses appear helpful (Penrose-Wall & Bateman 2006).

The vision

The strategic intent of this paper is to ask if current evaluation and service quality frameworks are helping NGOs to perform — are they helping consumers, or would agreed and some streamlining of approaches to RCOM make an additional contribution? To answer this we must touch upon all aspects of quality improvement as shown in Figures 1 and 4 to situate the place of RCOM to NGO program development and evaluation. The vision is this: RCOM would require networks of like-minded NGOs with similar functions and philosophical openness to adopt the tools and approaches of **evidence-based programming, not just outcome measurement.** This vision does not mean that these NGOs would *ONLY* use programs of proven value (ie that they would stop innovating new programs). But it does involve a more structured approach to programs and a philosophical synthesis of the various knowledges available that constitute 'evidence-based programming' (programs informed by research evidence). The vision is that services need to be clear on which domains of consumer problems they attempt to assist. From consumer data, agencies could potentially show which group/s of consumers use the service and which consumer needs are more likely to be actually met by the service (or other characteristics of interest). The findings would enable NGOs to estimate what other resources might have to be put in place to address needs that remain unmet, where it is reasonable that these be met by services as opposed to by the consumer. In both Victoria's psychiatric disability support NGO sector and in NSW public mental health services, increased Treasury resourcing flowed to mental health some years after RCOM was adopted. RCOM where it is applied appropriately and where it is quality managed, need not displace or corrupt the traditional functions and benefits of 'community work'. Rather, it is situated within community work and adds an additional program technology.

Figure 4:

Evidence-based practice



Adapted from Muir Gray 2001:xxii

In Figure 4 we adapted Muir Gray's understanding of evidence-based practice. That author privileged only epidemiology as the key knowledge base. By contrast, we included the bottom text box inspired by the Canadian Mental Health Association's report, 'Framework for Support' (Trainor et al 2004). We show how NGOs can reconcile the historical and cultural aspects of their programs which arise from community values ('community work') with the pressure for modern embracement of 'evidence based practice' and finally, consumer recovery knowledges. This is especially important given that consumers have profoundly challenged many professional knowledge claims. The Canadian MHA concluded that the tension between competing epistemologies is resolved for NGOs when it is realised that NGOs may have responded quite appropriately to communities all along, but without the research languages used by contemporary policy makers and without publishing their findings. (Indeed, Harding (1999) reminds us that 'outcome' is a research construction for what is really the unfolding of human beings across time and the lifespan). What may become evident through more structured evaluation of programs and via RCOM is that minor modifications of approach (in program planning and delivery) is sometimes all that is needed by NGOs that may result in expanded opportunities for meeting consumer needs better. Evidence-based programming need not be interpreted as a tool for thwarting NGO innovation. Moreover, older traditions of doing 'community work' and 'community needs analysis' are not discredited but have been added to by ways of organising community work within which attention is paid to the specific benefits for consumers and to documenting what is being learnt by the organisation.

Finally, and importantly, the vision of RCOM and evidence-based practice includes by Trainor and colleagues called, emancipating consumers from the perspective that we only see them as 'in need of services'. RCOM shows where 'service' is no longer necessary. The vision of this discussion paper requires that we focus attention on the interventions of NGOs, the bolded box in the middle of Figure 4, in order that ultimately, consumers take control and experience this emancipation.

Why not just apply the Victorian PDRSS experience?

We chose not to take for granted that outcome measurement is a 'good thing' based on the experience of Victorian NGOs in mental health ('PDRSS services') and public sector services use of RCOM since the late 1990s (Victorian Human Services 1999; Eagar et al 2001; Pirkis et al 2005; Trauer & Tobias 2004). Instead, we enquire deeply into the contextual issues for models of service and relationships between sectors in New South Wales before drawing conclusions about what NSW NGOs might do. We especially consider the integration of care between the public and NGO services. For example, MHOAT is used in NSW public mental health services and applies different outcome measures to Victorian NGOs and Victorian mental health clinical services. NSW public mental health services do not plan in isolation and NGOs have contributed by endorsing MHOAT for public mental health care. But this does not imply that NGOs should use MHOAT systems and tools. The NSW contextual considerations impact on the choices of measures and the fit of outcome measurement with the quality improvement of integrated mental health systems in this state. But we can learn from Victoria's considerable experience of having both NGO RCOM and public mental health service RCOM. The above questions take into account the size of the commitment of RCOM, the resources it requires and the characteristics of the NSW community organisations funded for mental health work.

Finally, there are options for quality improvement other than outcome measurement. For example, instead of RCOM we could simply audit NGOs in NSW against what current evidence based programs recommend, for policy and guideline fidelity (a quality assurance approach) and base quality improvement upon NSW Health service development guidelines. But we would then not know if we were being effective in practice: we would only be effective 'in theory' due to fidelity to guidelines, policies and programs used in other settings. We currently don't know *precisely* how NGOs deliver their programs. We explore this in the final chapter around the merits of each quality improvement approach with and without outcome measurement.

Readership

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

- we clarify key concepts in Chapter 2 as a basis for discussion;
- we report on a survey of NGO experience in using outcome measurement in Chapter 3;
- we report the international literature about the utility and acceptability of using routine outcome measurement in mental health in NGOs (Chapter 4);
- we provide options for applying specific outcome measurement tools;
- we discuss alternative approaches for quality improvement and suggest a way forward.

Recommendations are included in the Executive Summary and at the conclusion of each chapter.

2

PREREQUISITES FOR DISCUSSION – SOME KEY CONCEPTS

'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.

'Consumers should not be left to feel they are being 'processed' or 'being put into the computer' rather than being listened to. The use of outcome measures does not replace all we know about therapeutic alliance for ultimate outcomes'.

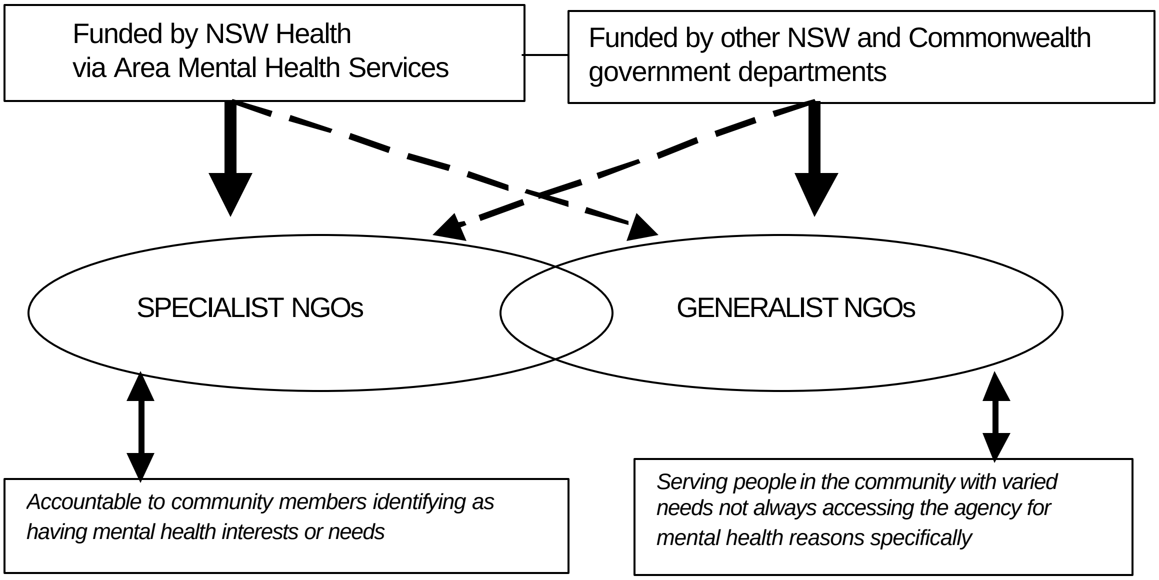
This Chapter outlines how we conceptualise NGOs in mental health and their fit within complex care systems. It provides background on current quality frameworks. While the Mratzek and Haggerty (1994) framework 'the spectrum of interventions', is the agreed national framework for planning mental health services for populations (it usefully conceptualises how to target interventions prior to, during or after an episode of illness) here we draw on other frameworks to make clear the unique challenges faced by NGOs when they plan their programs. We first take a structural approach then an intervention (what NGOs do) perspective. We introduce MHOAT and other RCOM systems in Australia.

Conceptualising categories of NGOs

For convenience, this paper refers to NGOs as either 'specialist' or 'generalist' organisations recognising that their functions differ. For example, each category may serve different groups of consumers, many NGOs have multiple funding streams but 'specialists' predominantly have Health funding (Figure 5). Specialists and generalists may also have different intellectual traditions. NGOs organise their membership base, fundraising and volunteers around these different perspectives about community needs. Figure 5 affirms a whole of government involvement in mental health across community.

The heavier lines in Figure 5 imply a stronger relationship for ‘specialists’ with NSW Health (Area Mental Health Services) but with important relationships with other government departments. Such organisations, we suspect, have historically identified as providers of ‘specialist mental health’ or ‘psychiatric disability’ services and have stronger care pathways and identifications in place with local specialist public mental health services. Many have secondary identifications as social welfare organisations or as broad mental health promotion organisations with operational linkages community-wide. ‘Generalists’, on the other hand, may serve wider groups in the community than those with mental health problems or disorders. Their clients may not identify with or be engaged with specialist mental health services. They may have less severe or more severe mental health problems, or their mental health needs may go unrecognised. Their clients may have not had treatment, may have rejected treatment, may have been rejected by treatment services or may not have benefited from treatment. These different client and organisational characteristics and functions have implications for the capacity of organisations and the utility of outcome monitoring with respect to meeting ‘mental health’ needs. The membership of management committees and workforces are also likely to vary: specialist NGOs are likely to attract career mental health professionals and consumers to their boards of management, executive staff, membership and workforce. The mix of NGO types is generally considered important for consumer choice. We treat each category separately for some aspects of discussion.

Figure 5: NGOs providing mental health care in NSW: accountability relationships



Primary vs specialist care

There is some difficulty if we try to situate NGOs along the 'primary care' or 'secondary/tertiary/ specialist' health care continuum. This is relevant to how we apply the available evidence about the outcomes of interventions to NGO settings because the research base for practice is either drawn from mental health care in general practice/primary care or specialist treatment settings and seldom is there research that relates directly to NGOs as a setting for care.

The World Health Organisation (1978) concept of primary care means a level of care delivery (first point of contact) but includes prevention, comprehensive, coordinated and continuous care. In Australia, primary care refers to community health centres, community pharmacies, general practice, private medical practice, school nurses, indigenous health, womens health, local government health services and consumer and community organisations (QLD Health 2002). By this definition, NGOs are assumed to perform primary care functions. Primary care has 'complementary' status adding to and balancing specialist care. NGOs in mental health agree that their programs are generally an adjunct to treatment services. Similarly, treatment services recognise that psychiatric treatment, especially medication on its own, without psychosocial interventions and support, will not achieve optimal outcomes for consumers (McGorrey et al 2005). There is two-way complementarity.

The terms, 'primary' and 'specialist' care were coined by organised medicine where general practitioners perform gate-keeping functions for specialists. It could be argued that these distinctions have less relevance to how other health disciplines and systems of care organise services. Severity and complexity of need is also a poor predictor of whether a service is primary or specialist care. While NGOs, like primary care agencies, provide continuing care and some focus on prevention, mental health NGOs may not identify as having 'primary care' functions. Suffice here it is to suggest that not all NGOs would identify with 'primary care' especially those who have decades of specialised expertise in working in mental health, suicide prevention, and rehabilitating persons with mental illnesses.

The relevance of this discussion is that policy and infrastructure are increasingly organised around integrating specialist mental health services into primary care as recommended by the World Health Organisation (WHO: 2003 a,c) since most mental health need presents to primary care (for example through general practice). The policy shift can leave NGOs invisible or poorly considered since they are spread across the system. Finally, policy frequently refers to NGOs as 'informal care' or as 'community groups' rather than as organisations with legitimacy as part of formal health infrastructures (primary and specialist care). This is also not entirely accurate. Some NGOs may design programs as 'informal' to optimise a social response to mental health need and they may have a blend of formal and informal approaches within the one program or within the one organisation. But funded NGOs remain an important health infrastructure and are thus, ‘formal’. There is also no doubt that informal care (natural relationships) is central to helping restore people after experiencing severe mental disorders. NGO capacity to engage informal care is a key service outcome and is highly valued, but this does not mean that the organisations are themselves ‘informal’ or that they do not require resources to understand, evaluate and further develop their contribution.

Within primary care in Australia we in fact have many tiers of very dissimilar services.

‘Social care’ and a social view of mental health

Mental health requires a social view of health and mental disorders are understood as requiring a biopsychosocial response (RANZCP 2005). In the UK, NGOs are termed part of ‘social care’ as Duggan et al (2002) show in Figure 6. These authors describe the centrality of partnerships in public policy which are aimed at ‘achieving synergies between disciplines, agencies, resources and interventions at the level of individuals, groups and communities’. Figure 6 shows NGOs to be part of ‘community health and social care support services’. NGOs straddle systems of care, engaging with each while also working to address the broad ’social, environmental and economic strategies’ that impact health. Table 1 lists the social components of a biopsychosocial view of mental health.

Figure 6: Duggan et al (2002) Partnership opportunities in modern health policy

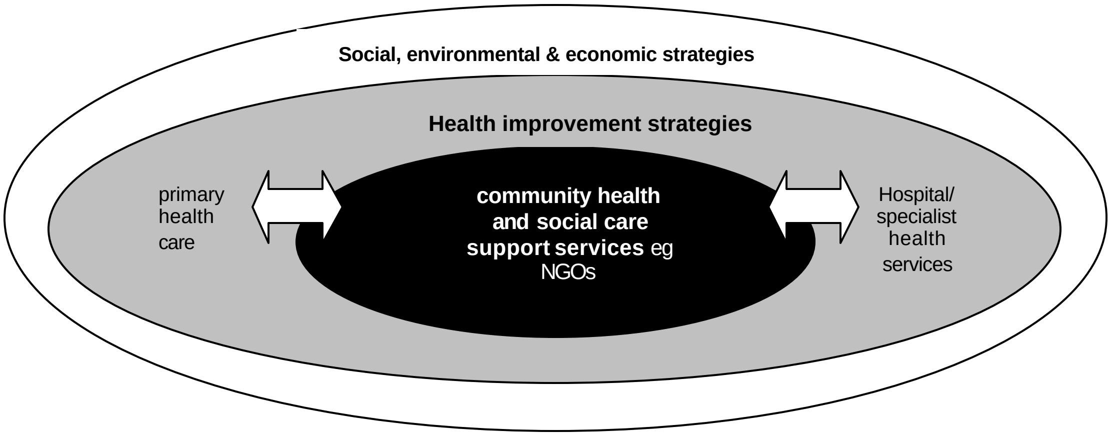


Table 1**: Social view of mental health**

1. Understands the complexity of human health and wellbeing.
2. Emphasises the interaction of social factors with those of biology and microbiology in the construction of health and disease.
3. Embraces the experiences and supports the social networks of people who are vulnerable.
4. Understands and works collaboratively within the institutions of civil society to promote the interests of individuals and communities and to critique and challenge when these are detrimental to these interests.
5. Emphasises shared knowledge and shared territory with a range of disciplines and with service users and the general public.
6. Emphasises empowerment and capacity building at individual and community level and therefore tolerates and celebrates difference.
7. Places equal value on the expertise of service users, carers and the general public but will challenge attitudes and practices that are oppressive, judgemental and destructive.
8. Operationalises a critical understanding of the nature of power and hierarchy in the creation of health inequalities and social exclusion.
9. Is committed to the development of theory and to the critical evaluation of process and outcome.

Applied from Duggan et al (2002).

Service integration as critical to outcome

Mental health systems are widely criticised for failing to integrate care in a way that is protective and responsive to consumers' needs (NSW Auditor General 2005, Commonwealth of Australia 2006, Groom et al 2003). Comprehensiveness is all-important (DeSisto 1995 a,b) without which integration cannot be achieved. Integration must include collaborations that aims to jointly provide services, or alternatively, sequentially to provide services in organised reliable (integrated) ways by different teams. NGOs have long recognised the importance of this and often formed to try to plug service gaps to make care more comprehensive. Outcome measurement in relation to varying degrees of service integration is the key strategic consideration in this paper in Chapters 4-5 since service integration complicates the question of attribution in RCOM since many consumers use public mental health ***and*** NGO services.

What do NGOs do? Distinguishing NGOs' 'mental health' work

'Clinical rehabilitation' vs 'psychosocial rehabilitation and support'

NGOs active in mental health in NSW generally do not provide 'clinical' services although there is no reason why they cannot elect to do so as independent organisations. There are exceptions: at least two have co-located psychiatrists and/or other medical staff (Matthew Talbot Hostel, OnTrack Community Resources) while others provide clinically oriented 'counselling' or individual therapies through allied health staff (Relationships Australia, Dympna House Inc and Co As It Italian Association for Mental Health Inc). Most NGOs assisting those with mental illness might be said to organise around the stress-vulnerability model and emphasise social support for preventing the onset of or relapse of mental disorders. In doing so, they do not necessarily employ 'clinicians' but a mix of professionals and lay carers who mobilise support or help consumers find and use support and resources in the community. They encourage the use of treatment as well as the use of support systems.

Many NGOs in NSW broadly subscribe to the key tenets of psychiatric rehabilitation or psychosocial rehabilitation as defined by the World Health Organisation (2001). These same ideas are also reported on some State government websites for specialist mental health services (see The Park service description, QLD Mental Health Services) and are included in the aspirations of specialist public mental health services (Herrman & Yellowlees 2001). More recently, clinical mental health services and NGOs attempt to bring together rather than separate the social and medical understandings of disability. Clinical public mental health services define themselves as providing the following:

- Reducing symptoms (NGOs do not provide treatment, but they encourage consumers to adhere to treatment and case management);
- Avoiding harms from treatments (All sectors aim to prevent prolonged hospital stays and NGOs traditionally provided 'aftercare' accommodation to achieve this);
- Avoiding disablement by improving social skills, including work and occupational functioning;
- Reducing stigma and discrimination;
- Family and carer support;
- Social support including in housing, employment, social networks and leisure;
- Consumer empowerment (enhancing involvement, self-esteem, self advocacy).

Many of these 'clinical rehabilitation' tasks of public mental health services overlap with both 'psychosocial rehabilitation' as understood by NGOs (Cnaan et al 1988) (Table 2) and 'recovery' principles as articulated by consumer researchers. While no one sector has a unique claim to particular roles in what has evolved as a crude division of workload, the orientation and focus of service providers in each sector has a bearing on the utility of and the selection of outcome measures. NGOs must select those measures most relevant to the roles of NGOs.

Table 2: Cnaan et al's (1998) Principles of Psychosocial Rehabilitation

1. Developing under-utilised potential
2. Equipping people with skills (vocational, social and living skills)
3. Self determination
4. Normalisation
5. Different needs and care
6. Commitment of staff in the belief progress can be made by consumers
7. 'De-professionalisation' of service (relationships emphasise support, not professional disciplines)
8. Early intervention
9. Environmental approach (a full social network is developed)
10. Changing the environment (resources in the environment are mobilised and attitudes are changed toward support for persons with mental disorders)
11. There is no time limit on participation
12. Emphasis is on strengths not deficits
13. Work centred process – work is seen as essential to building confidence
14. A social not medical model
15. Emphasis on the here and now

Some NGOs in NSW refer to their programs as 'psychosocial rehabilitation support' while others provide explicit 'psychosocial rehabilitation AND support'. The extent to which all consumers who need it can currently access broad psychosocial rehabilitation programs when they experience severe mental disorders in Australia is thought to be limited (McGorrey et al 2003). We can conclude that although the distinction between 'clinical rehabilitation' and 'psychosocial rehabilitation' is difficult and is without consensus in NSW (Fisher & Freeman 2005), psychosocial support underpins effective psychological and general medicine and all helping relationships and is thought to account for much clinical outcome in all settings (Priebe & McCabe 2006).

Victorian mental health Non Government organisations

'VICSERV' stands for, Psychiatric Disability Services of Victoria Inc. VICSERV's members adopted 'psychosocial rehabilitation' in 1992 and later, 'psychosocial rehabilitation and disability support' (PDRSS) as their key organising framework (Clarke 1998; Clarke in Pepper (ed) Victorian Human Services 2002). VICSERV members are principally but not exclusively

NGOs. The PDRSS sector grew from $6M to $45M in the ten years since it adopted this common service framework and RCOM (Clarke in Pepper (ed) Victorian Human Services, 2002).

Table 3: MHCC-identified service types of NSW NGOs

Service type of NSW NGOs active in mental health (Bateman & Johnston, 2001)	Number (%)
Consumer support groups (illness related)	160 (43)
Community consultative committees	36 (10)
Carer support groups	39 (10)
Supported residential services	33 (9)
Advocacy, education and information services	26 (7)
Open employment services	19 (5)
Telephone support services	18 (5)
Drop in centres and Clubhouses	13 (4)
Supported Employment Services	9 (2)
Consumer networks	9 (2)
Respite services	6 (2)
Outreach services	4 (1)
Total (services not NGOs)	372 (100)

Table 4: VICSERV-identified NGOs in Victoria identifying as PDRSS sector

Service type of (NGO) PDRSS services in Victoria (Victorian Human Services, 2003)	Number (%)
Mutual Support and Self Help Groups (MSSH)	Not reported
Home Based Outreach Support (HBOS)	Not reported
Planned Respite (PR)	Not reported
Residential Rehabilitation (RR)	Not reported
Psychosocial Rehabilitation Day Programs (structured & drop in)	One third of all PDRSS programs*

MHCC member organisations may not all have as strong and singular identification with ‘psychosocial rehabilitation’. The expectation that NGOs fit one paradigm may assist health planners and evaluators manage complexity but may be unrealistic in NSW in reality. An example of the varying intellectual origins of work within NGOs in NSW is suicide prevention whose NGOs have a poor fit under the ‘psychosocial rehabilitation and support’ paradigm. For instance, many grew out of a concern for young people found not to engage with treatment services or, who were not recognised as having eligibility for mental health services (and thus failed eligibility for 'psychosocial rehabilitation'). Working across population and individual approaches instead, these NGOs reached groups who would otherwise not have had a community response to their mental health and psychosocial needs. Screening and risk assessment were important. We cannot resolve the paradigm problem here, but we suggest 'resilience, recovery and rehabilitation' rather than 'psychosocial rehabilitation' alone, is a framework more inclusive of the intellectual heritage of more NGOs in NSW. Paradigms matter for matching evaluation and outcome tools to the conceptual integrity of organisations' work. Similarities nonetheless exist between NSW NGO and VICSERV members' service types (Table 3 and 4).

Who uses mental health-related NGOs in NSW?

Unlike Victoria, NSW mental health NGOs have no standardised **routine minimum data set** collection: they have no continually collected data about service user demographics and organisational processes such as length of service to each individual assisted. That it is difficult to profile service users over time at the level of state-wide analysis was identified by Bateman and Johnson (2000) who recommended that this demographic and service performance data be routinely collected as soon as practical. Without the latter, membership surveys are the only way to profile the programs provided by NGOs but this does not enable detailed information about service recipients or programs delivered. NGO Annual Reports are in the public domain, and report (often crude) service user demographics and outcomes. These may also be reported again to separate government departments against Funding and Performance Agreements. These mechanisms do not permit data to be pooled nor data manipulation to be performed to answer specific quality questions for the sector by the NGO sector itself.

Service outcome data are currently collected by NSW NGOs individually for reporting to funding bodies and as part of the National Mental Health Strategy ambulatory care data collection. However, it is not presently available directly to MHCC for use in supporting the sector's work. NGOs in mental health in NSW lack a data collection agreement (willingness of organisations to pool particular data for analysis) of the sort that can foster evaluation cultures across a system of similar organisations. An example of the latter is that which has been seeded in General Practice through Divisions (which are NGOs of GPs). Divisions were provided with start-up University support and evaluation units by their funders for jointly developing better GP-delivered patient disease management programs (refer to Diabetes Minimum Data Set, CARDIAB as examples developed by the University of NSW with Divisions of General Practice). That same infrastructure support is now needed by mental health NGOs to help the quality improvement of NGO-delivered mental health care.

By contrast, we have had maturing data sets available in Victoria since 1997: some 14,000 users of PDRSS were assisted in 1997. They were likely to have schizophrenia (53%), 18% had a comorbid disability (24% with intellectual disability and 30% a substance use problem) and 86% were on a disability support pension. In all, 64% had a clinical case manager from the public mental health system but not all had reliable case management contact. Referrals came most often from public mental health services (45-60%) and primary clinical support was provided by public psychiatrists (65%). Between 28-32% were new participants. Most participants were female (55%) (reportedly they are more likely to use self-help groups). Of the program participants, 89% were Australian born (Victorian Human Services 1997) which suggests maldistribution of NGOs or access limitations to particular groups. All service types are meeting increasing demand over time (Victorian Human Services 1999; 2003).

The overlap in the population served with that assisted by public mental health services confirms the sector's links with the specialist mental health sector. This is especially relevant to considerations about NGO outcome monitoring being a potential duplication with public sector outcome monitoring (in NSW for example, it may duplicate or need to be linked with MHOAT). Similar findings about the population were reported by NSW MHCC MAPS project (Bateman & Johnston 2000) but unlike Victoria, the MAPS data was not collected continuously through a minimum data set or routine consumer outcome measurement to reveal to us how the sector has changed in the past 6 years. It is clear that a knowledge base has been established in Victoria to assist NGOs in service development and quality improvement that NSW could also establish to support quality improvement.

In conclusion, current distinctions between sectors in terms of 'what they do' are pragmatic. They serve the purpose of a negotiated division of labour around the strengths and resources of respective sectors. But the distinction of 'who NGOs are' (independent, self determining and community managed) remains important in democracies and is thought to achieve complementary outcomes for consumers further to treatment outcomes. The operational distinctions are historical and structural rather than to do with distinct knowledge bases or entirely distinctive tasks performed by each sector. The clearest exceptions about what NGOs do or not do is that they do not undertake 'disease management' or treatment decision-making to clinically manage symptoms and they may not undertake 'clinical' case management. Further, they may not provide family interventions that contain 'treatments' for family dynamics but may provide information and support aimed to change family behaviours toward assisting a family member with mental illness. Therefore symptom based outcome measures will be more relevant to clinical services while measures that focus on social and occupational functioning, strength and quality of social networks and relationships, satisfaction and life quality will be more relevant to NGOs for quality management purposes.

‘Recovery’

NGO service philosophies vary between generalists and specialists. Specialist NGOs might argue they have always adopted a recovery-oriented approach seeing its overlap with the principles of a social model of health within ‘community work’. A review of conference proceedings shows that Recovery, as understood as a contemporary mental health consumer movement, has been explicit as a service paradigm in many Australian mental health NGOs since 1997-8 but implicit well before that time. ‘Recovery’ can be understood as a consumer self care knowledge base about how they experience illness, recovery, service use, and their citizenship, and, how they apply this personal experience to public health advocacy. Hope is central. External conditions (eg programs, attitudes) support or hinder internal recovery or what consumers do themselves (Jacobson & Greenley 2001). After extensive review of the international consumer literature, Ralph (2000) reports Recovery to be ‘*a process of learning to approach each day’s challenges, overcome disabilities, learn skills, live independently and contribute to society. The process is supported by those who believe in us and give us hope’*. Recovery has been much discussed and suffice it is to say here that recovery philosophy is now central to quality management in all mental health programs.

At issue here is whether or not individual recovery journeys can be subjected to consumer outcome measurement (VICSERV 2005). Onken and colleagues have assembled much of the rapidly growing international recovery literature. It generally embraces evidence-based programs and the involvement of consumers in shaping service directions through outcome measurement. Consumers have designed Recovery-oriented measures for assessing individual consumer needs and for organisational performance indicators (see Chapter 4). These must be synthesised into NSW considerations with local consumer dialogue and be scoped in a future Technical Paper on these measures. Many ‘recovery measures’ are measures of organisational style, workforce attitudes and programs, rather than tools for the monitoring of change in individual recoveries.

Clarifying ‘evidence-based programming’

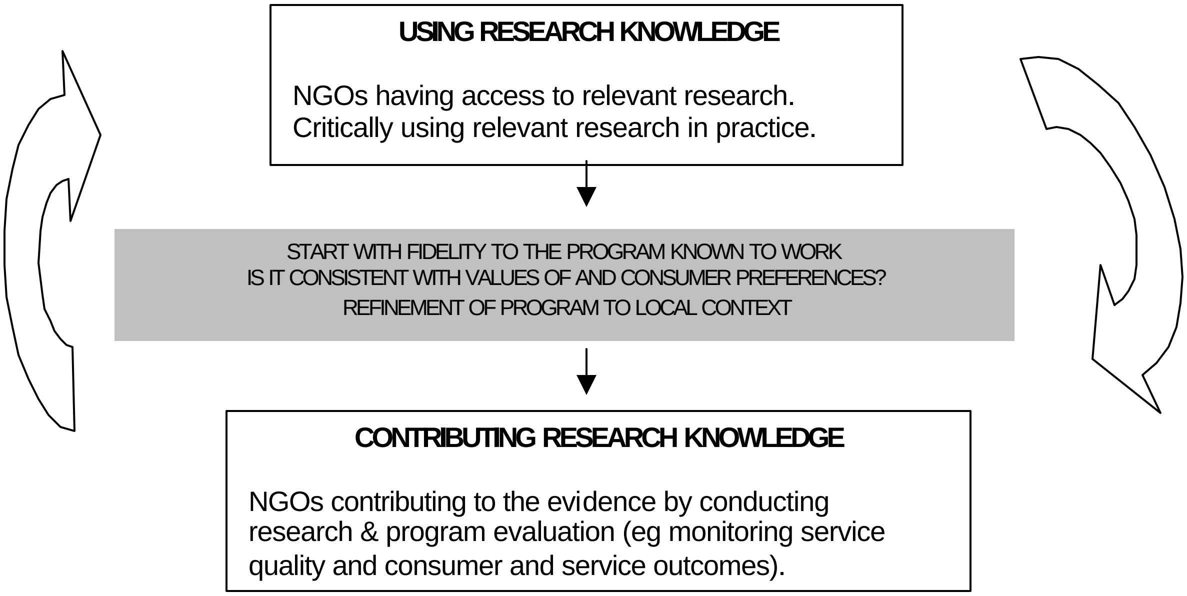
No one practises blind. Indeed all organisations evolve from diffused valued ideas or research. Evidence-based practice is conceptually important to outcome monitoring since outcome monitoring informs what we know works or does not work ie it informs evidence-based practice (Figures 1, 4, 7). ‘Evidence-based practice’ means, ‘using interventions for which there is consistent scientific evidence showing that they improve client outcomes’ (Drake et al 2001). At minimum it means to use research in one’s practice, although there is debate about which ‘research’ or ‘knowledge’ has privilege. 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).

Outcome data can inform local practice and state policy because it is systematically collected data similar to that used in research. Theoretically, agencies can apply their outcome data findings to improve their practice. An NGO might be said to practise evidence-based programming if a decision is taken to adopt outcome measurement because it establishes local directly-relevant evidence about the program and what it appears to achieve. The agency must standardise ‘assessment’ (‘intake’) procedures and records, use agreed interventions shown by research to work, and agreed tools such as ‘outcome measures intended to measure several domains expected to be influenced by the NGO program (McFarlane 2001). Programs would be evaluated ‘as you go’, rather than only afterwards.

There is currently research support from the United Kingdom and North America for many components of psychosocial rehabilitation programs of the kind performed by NGOs internationally and in NSW (Penrose-Wall & Bateman 2006). There is also confidence in assertive models of case management, taking into account that different models apply for different consumer groups (Rosen & Teesson 2003) and that these can and sometimes are performed by NGOs. But international research suggests that NGOs could modify their approaches for more effectiveness. But we do not have an adequate knowledge base to make these modifications with confidence since there is little research and formal evaluation of the Australian NGO-delivered mental health programs. A gap in research is a barrier to the uptake of evidence-based practice: NGOs face a clumsy task of applying ill-suited international research to their own work.

In summary, NGOs have opportunities to both use and contribute to the knowledge base as shown in Figures 4 and 7 if they adopt an ethos of program evaluation in the context of evidence-based programming. RCOM is one technology within such an approach.

Figure 7: Conceptualising evidence-based programming

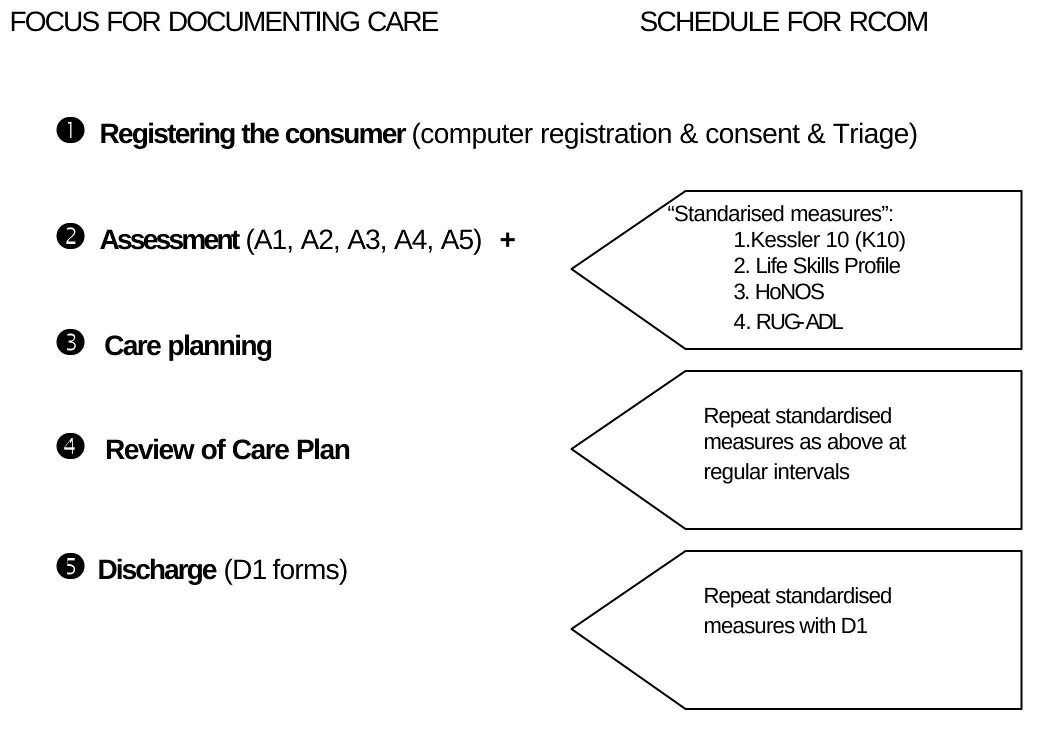


Consumer outcome measurement in NSW public mental health services

In this section we orientate readers to the content, structure and tools of existing selected routine consumer outcome measurement systems in Australia.

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 (Figure 8). 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. Data is then entered into the computer system about what care is provided and about the consumer. 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. They are only a component of MHOAT. By being repeated at regular intervals during the episode of care, the *change* in those measures is the ‘outcome’ for the consumer. MHOAT forms vary for different groups of consumers reflecting what is considered to be a good quality care process for children and adolescents, adults and adults over 65 years.

Figure 8: Conceptualising MHOAT in NSW public mental health services



FOCUS FOR DOCUMENTING CARE

SCHEDULE FOR RCOM

❶ **Registering the consumer** (computer registration & consent & Triage)

❷ **Assessment** (A1, A2, A3, A4, A5) **+**

“Standarised measures”:
1.Kessler 10 (K10)
2. Life Skills Profile
3. HoNOS
4. RUG-ADL

❸ **Care planning**

❹ **Review of Care Plan**

Repeat standardised measures as above at regular intervals

❺ **Discharge** (D1 forms)

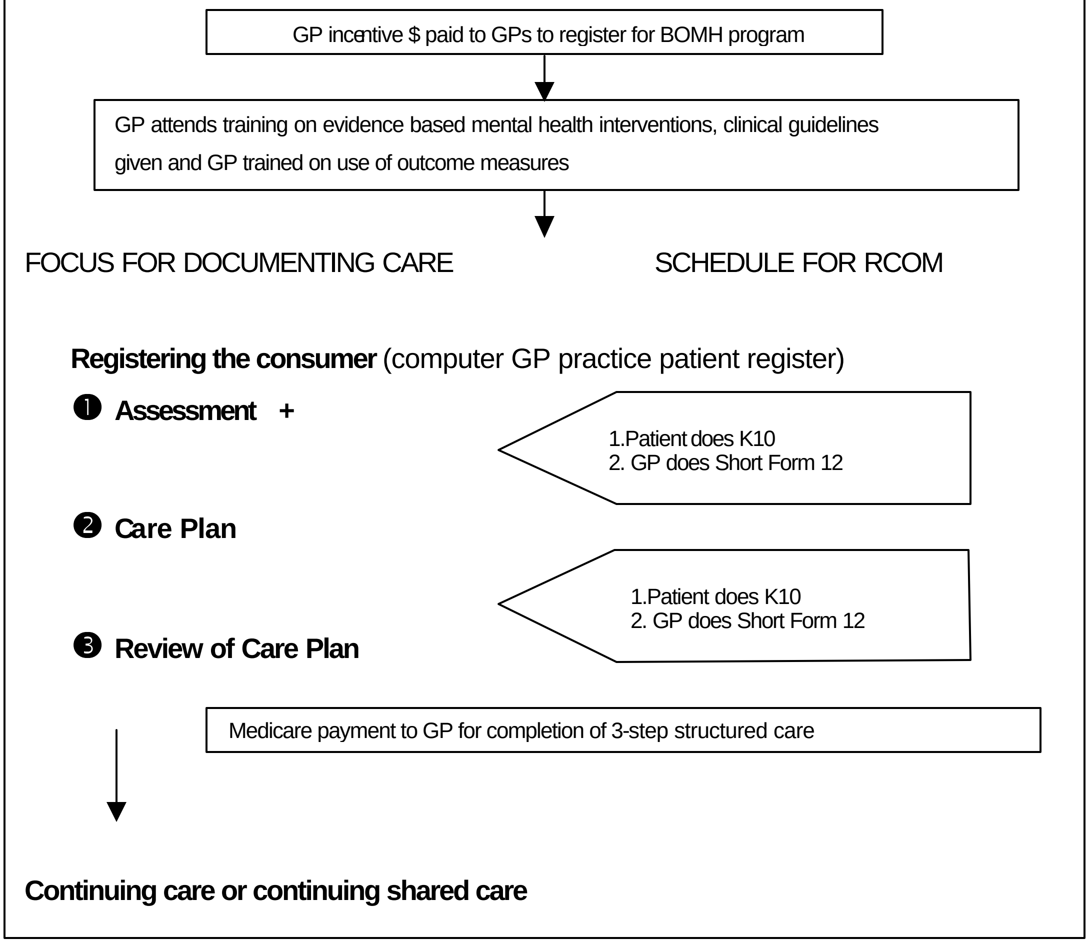
Repeat standardised measures with D1

The comprehensive assessment at intake includes the psychiatrist and/or case manager completing the ‘A1’ (12-page assessment booklet). It is used to summarise all tests and what is known about the mental health history, risk assessments, treatments, strengths and need for care. The doctor completes the A2: Physical Assessment (2 page form) if it is an inpatient admission. The team completes an A3: Family and Social Assessment (a 6 page form). An A4: Supplementary Assessment is not mandated, but may be used to summarise findings if a battery of other tests or risk assessments were performed. An A5 (2 page form) is being introduced during 2006 as a short version of the A1, for example, if the consumer represents the service soon after being discharged. The A1 remains on file for future episodes of care, but can be updated by new clinicians completing the D1 (Discharge), R2 (second review of care) or A5. MHOAT forms remain on file. The CoRE is the Consumer Relapse and Recovery Plan (not an outcome tool) and is prepared and held by the consumer and put on file if the consumer agrees.

‘**Standardised measures’ are the outcome tools**. These are done on hard copy then results entered into the computer by clinicians or clerical staff and in some locations they are entered into the computer by the clinician and consumer at the point of first use. These data can be retrieved from the computer to compare a consumer’s progress after treatment with how they reported feeling at their point of entry to the service. The concept is for data to be linked regardless of which NSW mental health service the consumer uses. Privacy legislation applies.

Staff access ongoing training through Area-based MHOAT support staff. In addition, a state-wide secretariat to support MHOAT (INFORMH) is located at Macquarie Hospital as a Unit of the Centre for Mental Health. They collect data state-wide for analysis. A data analyst is usually employed by Area Mental Health Services. Further to MHOAT Coordinators, Area and/or site-based Quality Managers and Hospital Executives champion MHOAT and assist clinicians to apply findings. Clinicians use the information for their practice with individual consumers while Executive and Quality Management staff use the data for management decision making.

Figure 9: RCOM in NSW by GPs in Better Outcomes for Mental Health

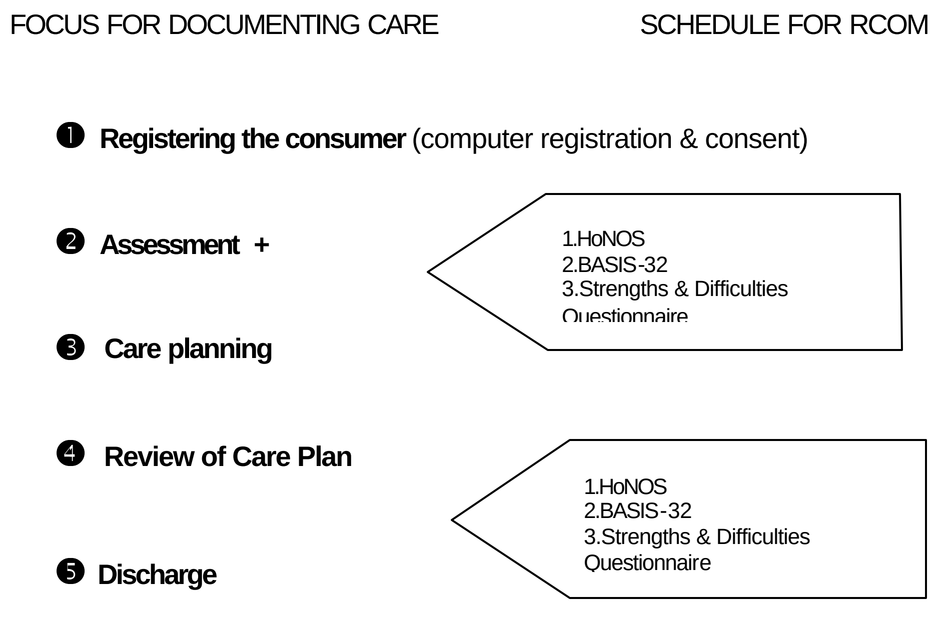


As these diagrams make clear, the goal is structured, documented care. RCOM must not exist in isolation from other components of quality care. The following is required by the agency:

- A model of care that involves providing services to individuals.
- An assessment system to assess and plan services with a consumer.
- A documentation system to record all planning and services provided.
- A system for monitoring outcomes about what was achieved (ie consumer health outcome monitoring or measurement).

Figure 9 is a simplified example of some routine consumer outcome measures for GPs that they can apply in the Better Outcomes in Mental Health Program. Diagnostic tools and Clinical Practice Guidelines, electronic downloadable outcome measures and referral database are available on the GP's desk-top computer. IT support is available through publicly funded Division of General Practice under the Divisions of General Practice Program. A national database of evidence-based resources, called 'PARC', is available through Flinders University, is also funded by the Strategy. All GPs are electronically networked and around 10% of GPs have registered for the BOMH. A national secretariat provides analysis of aggregated data from the BOMH initiative and a number of evaluation reports have been commissioned.

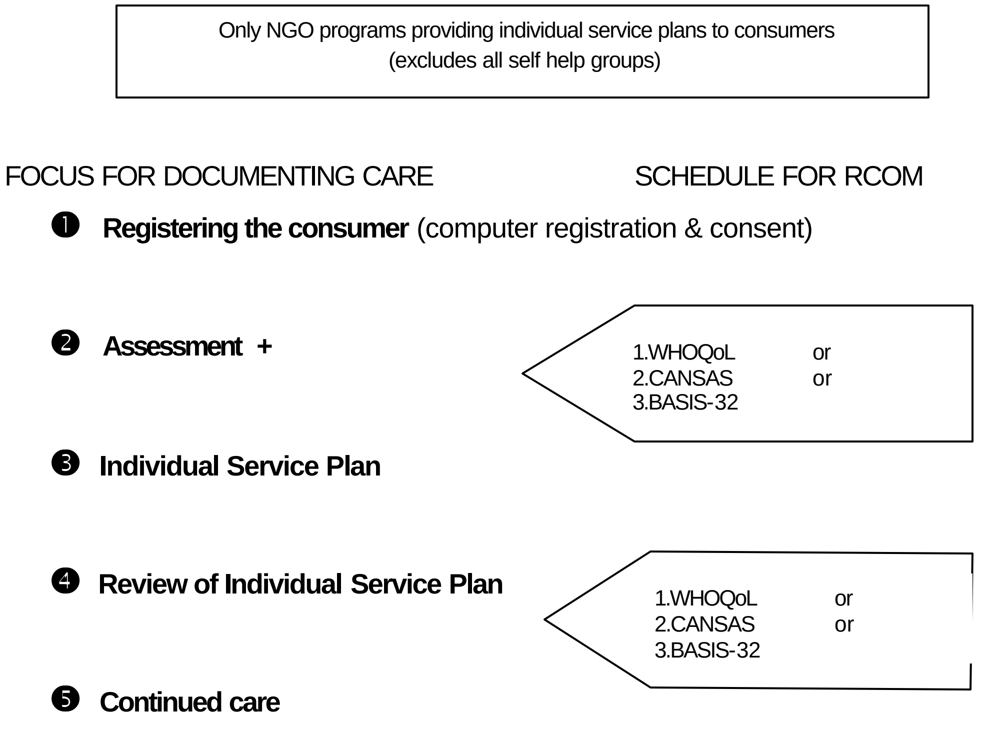
Figure 10: RCOM in Victoria's public mental health services



The Victorian Human Service website reports its experience and content of routine consumer outcome measurement (http://www.health.vic.gov.au/mentalhealth/outcomes/.htm). Victoria distinguishes between ‘clinical outcomes’ collected by Victorian public mental health services (since 2002-3) (Figure 10) and ‘PDRSS outcomes’ which focus on needs assessment and functional outcomes (Figure 11). Other measures are in use in different settings such as LSP-16, RUG-ADL, Focus of Care, CGAS and FIHS. Use of measures was preceded by consultation with consumers out of which a number of reports have been published (Smiggins Miller Consultants 2003). There is not standardised clinical documentation in Victorian health care records in which to embed RCOM but this is being worked toward. The literature review (Chapter 4) discusses commissioned reports of evaluation of these systems.

The PDRSS mental health NGO 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 because they generally provide group rather than individual interventions. This is not itself a problem, but some groups are unstructured or are based upon anonymity or participants.

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.

1. Outcomes for consumer (individual level)

2. Outcomes of NGO program (organisational level)

3. Outcomes for NSW consumers accessing NGO services (population level)

The first level is where consumers and workers appraise the consumer’s needs and preferences by completing and discussing outcome measures – some completed by the consumer, others by the worker, others done jointly. Consumers with brain injury or intellectual impairment may not always be able to participate (suggested to be around 18% of the NGO service user population). The completion of the measures is in the context of a structured comprehensive assessment (relative to the role of the NGO) and the outcome tools supplement the latter. Engagement and consumer satisfaction with the NGO critically relies upon this task being done with skill and optimising the communication between parties. Hard copy tools or direct electronic entry is used. In Victoria, the electronic entry system is shown in the Appendices. The goal is to compare reports from the first and subsequent contacts the consumer has with the service. It informs the Individual Service Pan but is not its totality.

A **second level of measurement** is when you pool the outcome data (de-identified and with prior consumer consent) from all consumers within the NGO for one-off evaluations for specific purposes or for an NGO’s annual report or submission for funds. How such reports might be expressed is given in the following examples:

“…During 2005, X% of consumers showed improvement on their HoNOS scores at X weeks after they entered our service…..”.

or

“HoNOS scores have remained unchanged for the group of residents who have been with our agency the longest. This was the group that had lived for over 16 years in psychiatric hospitals before moving to their flats and their average age is 66 years. The scores suggest that deterioration is being prevented despite their increasing age, which we interpret as a satisfactory outcome. Measures of life quality and satisfaction for the same group suggest that our service response to this group is meeting consumer expectations".

Another application for group reporting is that an NGO may appraise particular scores on an outcome measure for particular domains eg you might appraise the level of suicide risk or depression experienced by service users as a group (eg items 2, 3 and 7 on HoNOS) by generating these results for all service users for this item. You may then re-appraise if the service is adequately responding to this indicator of risk by auditing all agency responses to this risk factor and incidents of self-harm. Thus, the data enable you to be more sensitive to consumer needs. The critical skill is knowing how to interpret this information and plan an appropriate response. Quality improvement occurs only through action plans in response to the health outcome information generated.

The **third level in the use of outcome measures** is where all participating NGOs agree to submit de-identified information from level 1 into a State-wide or regional collection (eg housed at MHCC). When analysed, a brief report can be generated for NGOs about the performance of the sector rather than just within a single agency. Such a system does not meet all information needs for quality improvement but does provide member organisations with an infrastructure for quality improvement and health services research. At the State-wide level, the extent to which RCOM can inform the evaluation of services is discussed in the literature review.

Service 'process outcomes' (performance indicators for organisations)

Other approaches to quality management

RCOM should sit within a broader response to managing the quality of human services as shown in Figure 1. Other methods used for quality management include:

- Consumer involvement in staff selection and quality management.
- Complaint monitoring and response.
- Incident monitoring.
- Process outcomes (agreed performance indicators around standards that monitor the processes of care).
- Implementing relevant, current evidence-based Clinical Practice Guidelines.
- Implementing policy or State Service Development Guidelines.
- Audit of credentials of staff, accrediting staff and staff development.
- External audit of agency against Standards (Accreditation).
- Legal provisions such as Official Visitors and legal Advocates.

There are several philosophical approaches to how organisations manage quality using the above methods (World Health Organisation 2003 a; Carey & Lloyd 2001).

- Quality assurance (QA): audit against agreed standards or guidelines.
- Quality improvement (QI): or continuous quality improvement (CQI) in structures, processes and outcomes of care (which requires performance indicators of evidence of this improvement and health outcome monitoring).
- Balanced score card (BSC): takes into account the cost of continuous quality improvement and prioritises where quality improvement is most essential and affordable but where performance is being monitoring and managed simultaneously (World Health Organisation 2003). A 'report card' is often published for consumers so they know the quality performance of the service.
- Research, Evaluation and Development (RED): includes public health, health promotion and treatment/intervention evaluation research, and strategic rather than routine evaluation of structures, processes and outcomes of care (the traditional 'health services management research' approach). This remains essential regardless of what other quality programs are in place because it is creative, rigorous, may be internal or by individual investigators.
- Service redesign: 'Clinical Redesign' is a concept currently being implemented in some NSW Area Health Services. Design is required where reform need is so great that continuous improvement of the current system is inappropriate on its own and major redesign of systems is required (Carey & Lloyd 2001). Reorienting mental health services to recovery reforms is an example.

RCOM is considered the peak test of benefits of care for consumers because we have insufficient research to show that improvements in structures or processes of care directly impact outcomes of care (Pirkis et al 1999). However, on its own, routine or even strategic measurement of health outcomes may not itself improve the quality of service experience or outcomes for consumers and the extent to which it can be used for service evaluation is still being understood (Evans et al 2000; Gilbody, House & Sheldon 2003; Pirkis et al 2005; Harding 1994). As shown on page 1 Figure 1, health outcome measurement usually sits within a system of monitoring the **performance of organisations**: the inputs to organisation, processes of care, management and leadership and outcomes, called in much of the literature, 'process outcomes' or performance indicators.

Victorian mental health ('PDRSS') NGOs have both consumer outcome measurement and organisational performance measurement (minimum data set) in place as key components of their quality framework.

Current quality improvement frameworks and Accreditation

In public mental health services we have seen mixed approaches from the above list over the past decade with an increasing shift from the use of a QA approach and 'standards' to the use of service redesign and QI to improve collaborations between systems of care and between

NGOs and public sector services. There are more performance indicators for public mental health services in the EQuIP (Evaluation and Quality Improvement Program) than any other aspect of health care (ACHS, 2005) and they require elaborate data systems to monitor performance. QMS provides multiple standards frameworks for quality management, adopting continuous quality improvement for NSW NGOs (eg mental health, drug and alcohol, community health and prevention).

Specialist NSW NGOs active in mental health receive funding through various funding bodies. Funds are directed from NSW Health through the NGO Grants Program (via Area Health Services) as well as through specific Mental Health initiatives such as The Housing and Support Initiative (HASI). HACC, Disability Support Program in DADHC, Boarding house Reform Strategy, Drug and Alcohol Programs, SAAP, Commonwealth Disability Employment, Department of Community Services have separate standards and accreditation processes including mandatory processes (Table 5).

Table 5: Australian Quality Improvement frameworks

PROGRAM
EQIP (Evaluation and Quality Improvement Program)
National Mental Health Standards
QMS (Quality Management Services)
HACC (Home and Community Care)
Standards in Practice
Commonwealth Disability Employment Standards
Various clinical practice and service development guidelines

Both EQuIP and QMS now incorporate the National Mental Health Service Standards. Commonalities among standards frameworks include: Access, Assessment, Individual Service Planning, Consumer and Carer Involvement, Service Management. The standards have “devil is in the detail” creating much cumbersome work for NGOs. None take a public health approach to accommodate NGOs that provide health promotion through community development, advocacy, information, social marketing and awareness work and education strategies. The Glossary defines quality in relation to these programs.

The multiplicity of standards led MHCC to prepare a funding proposal to NSW Health to develop an overall framework, which would incorporate all these different standards and allow NGOs to meet the requirements of all funding bodies under a single process. This framework, successfully developed and piloted by QMS, is known as the Generic Framework for Human Services. It has not been used widely because of lack of coordinated action by government, although DADHC's Integrated Monitoring System incorporated the concept of the Generic Framework.

We need to streamline the application across NGOs of these quality frameworks. NGOs require free time for service review, redesign and development considerations other than the meeting of government requirements. The active support of NSW Health, DADHC and other government agencies is needed to do this, and is currently being explored within the Grant Administration Review within the Premiers Department.

For these reasons, we used in Figure 1 a simplified 'building blocks' of quality in the front of this paper for the purposes of discussion so that NGOs and other readers could situate RCOM in relation to the many other components of quality management infrastructure.

Summary

Approaches to defining and managing quality are now sophisticated (Renhard 2001:7; Muir Gray 2001; World Health Organisation 2003 c). The move to a comprehensive evaluation approach through QI (or CQI) is evident across the health and human service systems with numerous information collection processes. They represent attempts toward adopting evidence-based programming. There is now much expert, administrative and practitioner / worker experience in outcome measurement in other health care systems. Quality improvement and service redesign around partnerships appear favoured at present in recognition that while independent surveyors or researchers might from time to time audit organisations to see if their practice meets guidelines or standards, episodic reviews result in stop–start change relying on expert leadership drive. Further, no amount of continuous improvement will correct faulty design. QI must be embedded into the culture of organisations not just within the funding arrangements and NGOs need to manage organisations not just their relationship with Government for organisational survival. All staff must be able to contribute to improvements continuously and opportunistically (World Health Organisation 2003 c:12) informed by relevant data. Consumer health outcome measurement remains necessary but insufficient for quality management needing to be supplemented by organisational improvement and research. Similarly, quality frameworks without health outcome monitoring are viewed as deficient. While NSW NGOs are reporting outcome data to their funding bodies, the data are not accessible to NGOs as a sector in consumer and organisationally de-identified ways. This lack of industry-based quality infrastructure suggests that MHCC member organisations when viewed as a system of care, lag behind other Australian mental health quality management systems. The latter are described by Pirkis and colleagues (2005a) as beginning to show promising results so are worthy of NGO consideration.

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.

3

SURVEY: NGO EXPERIENCE WITH ROUTINE USE OF OUTCOME TOOLS

> *''It is difficult to provide for consumers' needs relating to social, leisure and recreation, due to funding limitations".*
>
> *NSW NGO respondent to 2005 MHCC outcome survey*

> *"the measure made me realise how chaotic my life was …it helped me and my worker work out what I really needed. It helps me feel a part of things".*
>
> *Consumer in UK's MIND (Mental Health Association) on using the Avon Mental Health Measure.*

Introduction

In July 2005, MHCC held a Strategic Discussion Forum with member organisations on measuring consumer outcomes. In preparation, MHCC surveyed members about their current practice in formal assessment of service users and outcome measurement. The survey was administered by email/mail and was called, 'Assessment and Outcome Measurement: How do you know you are making a difference?'.

Results

Of 144 organisations surveyed, 33 responded (23% response rate), being 34% of service-providing NGO members. Of these, 28 (85%) provide services for consumers; 4 (12%) provide services for families and carers and 1 organisation (3%) provides advocacy services only. Of responding organisations, 48% have fewer than10 paid staff; 40% have more than 20 staff. Volunteers work in 8 organisations. Earlier surveys by MHCC (Bateman & Johnson 2000) inform us better about the size, roles and workforce characteristics of the sector however, respondent organisations nominated a range of service types (Table 6). Many organisations offer more than one service type.

MHCC asked what program and activity data are currently recorded by services. Organisations collect between one and 13 items as shown in Table 7. When asked if the funding body has particular requirements regarding the collection of activity data, 70% reported having to meet imposed activity data collection. When asked would a standardised data collection tool for use across the NGO (mental health) sector be helpful, 65% of respondents reported that they would like to use this if it existed.

Table 6: Services provided in 2005 by responding NGOs (N=33)

Type of service	No organisations	%
Supported accommodation	18	54
Employment or supported employment	11	33
Telephone support	10	30
Support groups	11	33
Recreation and leisure activities	10	30
Centre-based rehabilitation	7	21
Respite care	5	15
Advocacy, information, education	16	48
Other, incl counselling & family support	14	42

Table 7: Information routinely collected by NGOs in mental health in NSW

Waiting list of service
Duration of engagement
Primary diagnosis
Dual diagnosis
Age Numbers accessing services
Occasions status
Referral pattern prior to entry to NGO
Re-admission to hospital
Exit from service
Gender
ATSI status
CALD (Culturally and Linguistically Diverse) status

One organisation commented: 'Staff have stated that an across-government approach to a standardised data collection tool for the NGO sector working in disability services would be extremely helpful as it would streamline service delivery and allow for more fruitful discussion about gaps in services, the need to change service delivery….'. Most others replied that they are already locked into a data collection system required by their funding body. Examples given included the National Data Collection Agency for SAAP-funded services.

Assessment of consumers' needs

Organisations were invited to say how consumers are assessed prior to or at entry to the service. Varied methods of assessment (or none) reflect the very different services provided. Many organisations use more than one assessment method, 81% use their own assessment format, and for 9 organisations (27%), this is the only assessment tool they use. Five large NGOs reported the additional use of formal (validated) assessment and outcome tools (Table 8).

Table 8: Validated outcome measures used by NGOs in NSW

- Life Skills Profile 39 (LSP 39) (3 organisations)
- Kessler 10 (K10) (2 organisations)
- Health of the Nation Outcome Scale (HoNOS)
- Global Assessment of Functioning (GAF)
- Camberwell Assessment of Need Short Appraisal Scheme (CANSAS)
- Behaviour and Symptom Identification Scale (Basis 32)
- Psychosocial Rehabilitation Outcomes Toolkit
- Quality of Life Scale (QOLS)
- Role Functioning Scale

Other forms of assessment include risk assessments and a 'Clinical rehabilitation/disability support checklist' is in use that was developed by an Area Health Service for use by one NGO. Finally, two organisations jointly administer these tools with their local public Area Mental Health Service where the consumer is referred by the mental health team. They use the standardised measures within MHOAT (K10, LSP, HoNOS).

One organisation noted that different assessment processes are used for different services within the one organisation. Another reported that the referring organisation provides the assessment and an intake interview is conducted with prospective consumers being referred to the NGO.

When asked how organisations assess whether or not they meet the identified needs of a prospective consumer, responses included:

- that the interest of prospective clients, their willingness to engage, and the compatibility of particular consumers (for shared accommodation) all influenced how the NGO assessed their needs and whether or not they could meet the expressed needs of individuals;
- ongoing identification of client needs in assessment and individual planning;
- consultation with the referring organisation for satisfaction with the NGO, was a proxy measure of the extent to which the NGO met, or was perceived to meet, client needs.

Eligibility and exclusion criteria were mentioned as impacting on the extent to which NGOs can accept particular clients. Risk assessments of the history of particular behaviours sometimes meant that the client met exclusion criteria. The willingness of other services (especially health services) to support clients in their NGO placement impacted on the NGO's capacity to accept clients and to meet their needs. 'Staff resources and skill base', and 'staff and volunteer training' were other capacity considerations. One respondent noted, (this) 'agency has standard skills and qualifications for employment and has benchmark standards in disability services and mental health'.

Individual consumer care planning

When asked if there is a structured process for the development of an individual care plan and if the plans are developed with consumers or other interested parties, 76% of respondent organisations reported that they use a structured process for care planning with the consumer. This was not applicable to the work of 12% of organisations (eg those supporting carers), and for 5% of organisations, their work does not include developing an individual care plan (eg an organisation working with homeless people in very short term shelters). Furthermore, 62% of respondents develop care plans with the involvement of other interested parties always or sometimes being, a carer, Area Health Service, other government agency (eg HACC), other NGO, Guardian, GP or the Office of Protective Commissioner. The survey found that many NGOs use a structured process to review the care plan and further develop it: 63% of respondents (n=21) replied 'yes', 15% (n=5) replied 'no', while 21% (n=7) reported that this was not applicable.

Outcome Evaluation

We asked if organisations use a 'consumer satisfaction' or 'service evaluation tool'? In all, 76% of respondents use these 'always' or 'sometimes'. One organisation commented: '(the organisation) strongly supports a model of consumer participation in the planning of its services at the local level. As a result a yearly consumer satisfaction tool is circulated for completion, with the assistance of consumer advocates.'

Information was collected on what mechanisms organisations use to understand how service interventions have an impact on the health and quality of life for a consumer. Responses show the range of ways in which it was understood:

- Review of plan with consumer to ensure access to generic services achieved within framework of rehabilitation and recovery; formal evaluations
- Quality of Life assessments attached to individual plans
- Case meetings, observation
- Consumer feedback and satisfaction surveys; follow up questionnaires
- Consumer meetings run by consumer advocates
- Self-reporting; skill development;
- Annual survey of volunteers, health professionals
- Occasions of hospitalisation
- Outcome tools completed by consumers, or consumers and clinicians, as listed in the response to question 6, including: CANSAS, Basis 32, Role Functioning Scale, Life Skills Profile (3 organisations) Psychosocial Rehabilitation Outcomes toolkit; HoNOS, GAF (General Assessment of Functioning);
- Consumers of at least one organisation, referred by the local mental health service, are involved in the MHOAT review process.
- Targets/review of employment goals; Maintaining employment
- Reports against Key Performance Indicators

Continuing this focus on explicit measurement of health outcome, organisations were asked if there is a link between how consumers' needs are assessed on entry and how outcome is evaluated?' Of responding organisations, 54% replied 'yes' while 30% replied 'no'. The question did not apply to some organisations. Responses included:

- Link through original care plan and progress achieved at review of each agreed goal;
- 'Assessments identify needs. Outcomes are the result of meeting the need.'
- Information from the assessment feeds into individual program assessment and plans.
- Individual client profile and client risk profile on entry; reviews measure outcomes and progress
- 'The link would be through the original individual service plan and the progress achieved at the review of each agreed goal. '

Further, 51% of respondent organisations have a formalised process by which the consumer outcome evaluation contributes to the quality improvement process, while 42% replied ‘no’, one said a process is under development and 7% said the question is not applicable. Overall, 33% of organisations were reportedly happy with existing mechanisms, 18% are currently reviewing their process, and 30% are not happy. Seven of 9 services providing supported employment or an employment service (either the only service type or part of a mix of services) are generally happy with the mechanism used to assess consumer outcomes.

Finally, we asked for organisations to report any other issues and comments. Responses provide us with only a limited insight into sector attitudes to outcome measurement and resource needs are evident:

- ‘It is very hard to measure outcomes in an industry such as ours.’
- ‘Outcomes for consumers are difficult to measure’.
- ‘We recognise the importance of outcome evaluation and are taking steps to improve this process’.
- ‘Training/funding issues for outcome measurement’.
- ‘It is not part of a structured process’.
- ‘Not linked to funding or organisational performance’.
- ‘Not consistent across different programmes’.
- ‘Not resourced to be undertaken comprehensively’.
- ‘Difficult to provide for consumers needs relating to social, leisure and recreation, due to funding limitations’.

NGOs’ views of consumer health outcome tools

We followed up some MHCC members to further enquire about their experience with the outcome tools they identified as in use in the survey. Some reported that they are not viewed as a major source of help in service development but may be useful in the therapeutic work done with individual consumers. This information was gathered by telephone interview. It is de-identified to enable organisations to speak freely without potential risk to their funding and performance contracts with Area Mental Health Services or other funding bodies. In some cases, these mandate that the NGO apply particular outcome measures.

Organisation A:

This large provider of services for several different client groups is contracted by the Area Health Service to complete parts of MHOAT when they register a new client with the Area Health Service. They are responsible for completing the A1 ‘assessment of current presentation’ (12 pages), and a data registration from. Subsequently, at 13-week intervals, they complete the MHOAT form SMI (the ‘standardised measure’ which incorporates LSP-16 and HoNOS). Staff can be trained to use these tools in about 2 hours and the training is provided by the Area Health Service. A handbook is provided to assist with the scoring of HoNOS. Consumers are invited to complete K 10, the consumer self report measure used in MHOAT. The organisation reports: ‘Consumers generally experience no difficulty with their one pager, though staff report that they dislike completing the forms every 13 weeks and generally refuse’. This organisation does not find the MHOAT forms useful, and they do not add to work being undertaken.

Organisation B:

This organisation, providing accommodation support, day programs and outreach support, uses the Camberwell Assessment of Need Short Appraisal Scheme (CANSAS). The CANSAS is a one-page form made up of series of four questions about the level of assistance required and received in 22 domains of health and social need. The organisation relies on a clear assessment of need in enabling it to plan and to tailor services to individuals’ needs. CANSAS is the tool for use by consumer and staff member together and is administered by structured interview every 6 months. It informs the consumer's Individual Service Plan. Training in using this tool is given to all new staff. It takes a problem-based approached rather than addressing psychopathology. This organisation also uses the BASIS-32 (McLean Hospital), a 32-item consumer self-rated tool, designed to assess the consumer's perception of his/her mental health. The consumer answers the questions by reporting the degree of difficulty with functioning or symptoms. The organisation finds (in line with other research on this measure) that consumers provide reliable and valid assessments of their mental health status and that this tool is valuable in providing an ongoing record of changes. The organisation was rigorous in researching which tools to use, and has further adapted the CANSAS to its own needs. Opportunities were provided for staff to voice concerns and to be part of the decision making process. The organisation finds both tools of great value in its work.

Organisation C:

This organisation provides supported employment, supported accommodation and recreation. They have used a number of consumer outcome measures, but have not always used the whole tool, finding it more useful to their purposes to use the parts of direct relevance to client circumstances. They have used the LSP, the Role Functioning Scale, and the Quality of Life Scale. They stress that it is hard to achieve consistent use of any outcome measure given staff changes and training needs. They have also met difficulties with data evaluation, and without this, the measures are only valuable in work with an individual, and have no comparative value organisationally.

Organisation D:

This organisation provides extensive services to clients with a range of different needs, through many different service types. Consumers are invited annually to comment (via a recognised consumer satisfaction tool) on satisfaction with the services they receive. This organisation is involved with research introducing a new way of working with consumers. A range of tools to measure outcomes are involved in this work (including the MHOAT standardised outcome measures) but results are not yet available and it is too early to know how the tools make a difference.

Organisation E:

This is a large organisation running accommodation support services. Like organisation A, for Health-funded consumers, they do joint assessments with Mental Health Services, using MHOAT. They are actively exploring options for consumer outcome measurement and ongoing data collection. They are considering using LSP 39, which they see as of much more value than LSP 16 in the context of recovery and client choice. The organisation expressed awareness of the lack of resources for work relating to evaluating consumer outcomes and the limitation this puts on organisational development.

Discussion

We have reported findings from a non-representative sample of NSW NGOs to a mailed survey regarding their views about and experience applying health outcome measures and formal care processes. While the response rate is disappointing, it is consistent with discipline-based surveys in the mental health field, which seldom achieve more than 30-50% response rate. Findings suggest preliminary significant interest in RCOM and indicate a need for support to NGOs for formalising processes of care assessment and to link it appropriately with service evaluation. In all, 9 different validated tools were in use, of which, 2 were recommended for specialist mental health services by Andrews et al (1994) and the LSP was acceptable but at first not recommended because of cost. This is promising given that Australian RCOM data reports higher agreement from academic than practising psychiatrists and it has had a mixed reception in specialised public mental health services (Pirkis et al 2005; Trauer 2004). Internationally it has attracted negative opinion amongst substantial numbers of private and public psychiatrists (Gilbody, House & Sheldon 2002). Mixed reports exist in child and adolescent mental health settings with psychiatrists having less favourable opinion than psychologists and staff (Huffman et al 2004).

While the low response rate precludes us drawing firm conclusions (other than need for interview-based face-to-face or telephone surveys) we did scope tools and needs and from field knowledge, we suspect little other formal outcome activity is occurring. Nonetheless, some organisations are exposed to and are grappling with administering, financing, managing and interpreting health outcome data. Using information from earlier MHCC member surveys (Bateman & Johnson 2000) with a better response rate, we are aware that at least 78 of 372 NSW NGO mental health programs (21% of programs) could potentially apply RCOM if willing, resourced and supported to do so. These include supported residential programs, open and supported employment, centre-based and Clubhouse programs, and outreach services.

We have noted how NGOs came to use RCOM. Some initiated use relevant to their distinct service model and needs and might be said to have a true health outcomes culture within the organisation. These 'experienced early adopters' are an important group for encouraging others in the sector. Others are exposed by virtue of their existing funding contracts or service integration with Area Mental Health Services with a good operational experience. We need to know what workforce support actually exists in this group and what compliance there is with outcome measurement of these participating NGOs. A final and larger group show familiarity and interest having designed their own tools for regular use – or the 'flag interest group' but these too appear to have a pre-existing outcome oriented culture. Each group is likely to have different development needs. We detected no disagreement with or considered argument against the introduction of these tools where appropriate.

Conclusion

The hub of experience in the application of validated health outcome measures we identified within NGOs in NSW and the larger group (at least a quarter of MHCC member agencies) who use structured assessment with client follow up, suggests mental health NGO receptivity to RCOM. This is a basis for capacity building. Users were, not surprisingly, principally specialist NGOs whose interest was mental health outcomes specifically as well as wider welfare outcomes and needs satisfied for consumers attending their programs. There is limited experience in partnership arrangements where data are collected for two organisations' purposes and are shared between cooperating organisations, such as applying MHOAT between a cooperating NGO and Area Mental Health Service. More detailed needs analysis is now needed at the workforce, consumer and management levels with the view to obtaining a census or representative survey sample to better inform the NSW NGO Development Strategy Workforce Reform, Quality and Outcomes, and Partnership programs.

Refer to Recommendation 1 above: the need for representative workforce data to fully inform next steps in RCOM.

4 LITERATURE REVIEW: The utility and acceptability of routine health outcome evaluation through NGOs for resilience, recovery and rehabilitation programs

Introduction, aim and scope

The questions this literature review seeks to answer are:

- Is routine consumer outcome evaluation useful and acceptable in selected specialist mental health NGOs for their resilience, recovery and relapse prevention work and should NGOs *routinely* evaluate consumer health outcomes as part of their quality improvement framework?
- Is there a role for routine outcome measurement for generalist NGOs who may serve people with or suspected to have mental disorders?

Our focus is outcome measurement in relation to planned worker-consumer interventions or structured peer-to-peer interventions that may generate social and health outcomes for consumers. This is in contrast to the broader social capital benefits that may accrue from participating in community organisations. (This is a separate literature on social structural determinants of health and generally affirms the importance of NGOs for fostering positive social milieu, social inclusion and the promotion of mental health). The review takes into account 'utility' and 'acceptability' at three levels:

- not identify as part of the specialist network of mental health services but who
- might consumers find RCOM useful and acceptable?
- might NGO care providers find it organisationally useful and acceptable?
- might NGOs collectively find RCOM useful and acceptable as a quality improvement infrastructure?

We include all reports specific to NGOs' use of, and NGO development of outcome measures. Space does not permit us to include all published accounts of the studies that field test all the measures that NGOs currently apply so we rely on the most current secondary research and systematic reviews of the utility of the measures or their evaluation as a quality improvement technology.

Method

Two researchers (JPW, SB) independently retrieved information from Embase, PsycLIT, PsycINFO, Pubmed, CINAHL (Citation Index of Nursing and Allied Health Literature), Medline (2000-2006) Cochrane DARE, Cochrane CENTRAL, Cochrane Database of Systematic Reviews (2003-2006) and Social Work Abstracts (1994-2006). For efficiency, searches did not predate the ‘Measurement of Consumer Mental Health Outcome’ publication for the National Mental Health Strategy by Andrews and colleagues (1994). Only a three-year period was included in the Cochrane searches since a Cochrane systematic review on the topic included data to 2003 and included these databases (Gilbody, House & Sheldon 2003). Searches used various combined terms: ‘outcome measures’, ‘routine monitoring’ with ‘mental health’ and ‘psychosocial rehabilitation’, ‘measuring recovery’, ‘case mix’, ‘screening’, ‘employment outcomes’, ‘relapse prevention’, ‘health care assessment tool/scale’, ‘mandatory/mandated outcome measurement’ and quality management terms. We used ‘non government’, ‘NGO’, ‘non state’, ‘non statutory’, ‘voluntary organisations’, ‘charitable organisations’, ‘community organisations, ‘partnerships’, ’managed care’ and ‘social care’ to locate NGO studies. We also searched Google by the names of key international mental health NGOs and by outcome tools. We limited diagnostic searches to ‘schizophrenia’ and ‘depression’/ ‘mood disorder’ outcomes. We confined searches to adults but there exists a large science on outcome measurement for child and adolescent mental health issues. We did not address eating, anxiety, substance use or personality disorders.

We also manually searched the table of contents of these journals: Australian and New Zealand Third Sector Review, International Journal of Psychosocial Rehabilitation (1997-2006), New Paradigm (the journal of VICSERV), Community Mental Health Journal (1994-2006), Social Work in Mental Health (2002-2006), Journal of Epidemiology and Community Development, Psychiatric Services (2000-2006), Australian Journal of Primary Health (2001-2006) and Australasian Psychiatry. The remaining two reviewers (TO, JB) considered the relevance of materials retrieved. Reference lists were scanned. NSW NGO websites and Conference Proceedings were searched.

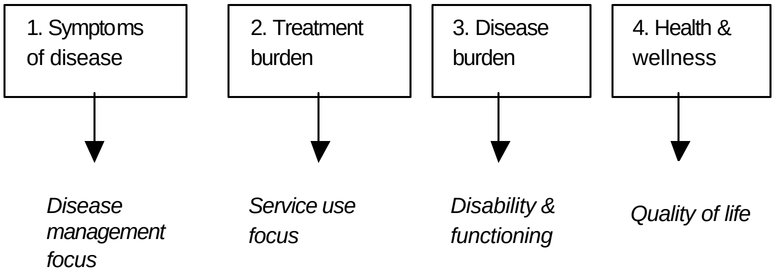
Results summary

Of the vast health outcome literature most deals with treatment effectiveness and efficacy for reducing symptoms rather than psychosocial outcomes. We found three evaluative articles in the peer reviewed international literature of direct relevance to NGOs’ outcome tool use in psychosocial rehabilitation and recovery programs. Of these, one was an Australian descriptive account (Trauer & Tobias 2004). An earlier report of the same study was published as Tobias

& Trauer (2003). We found website accounts of NGO experience in RCOM and conference accounts of implementing RCOM. We found a systematic review of RCTs evaluating if routine outcome measurement in mental health improves care and outcomes for consumers (Gilbody, House & Sheldon 2003) and recent commissioned reports and a systematic review of the measures commonly used in the Australian public mental health field. Due to space limits, we include only a sample of studies reporting factors determining uptake of RCOM, practicalities, utility and limitation of such systems for quality improvement to overview the key issues for NGO consideration.

Literature conceptualising outcome measurement

Health care is conceptualised as including 'formal care' (services), 'informal care' (by relatives, friends or neighbours) and 'self care'. At the level of broad public health policy, literature describes four domains of outcome as follows and each provides information for different forms of public health response.



Gardner and Nudler (2002) identify an alternative categorisation of consumer outcomes:

- *Clinical outcomes*: concerned with changes in a consumer's symptom status.
- *Functional outcomes*: concerned with changes in skills for daily living, social, or employment skills.
- *Personal outcomes:* issues identified by individuals as important in their life.

The authors conceptualise these as follows. 'Clinical outcomes' may be measured by using standard methods from health and social sciences fields with focus on symptoms or risk status for complications of the disease. 'Functional outcomes' may be assessed by measuring the individual's functioning before and after intervention by carrying out in-situ assessments while a consumer shops or cooks a meal (traditionally functional assessments have been carried out by Occupational Therapists in mental health services). Functional assessments may also be carried out using similar tools that systematically rate the consumer's skills in a number of areas or domains (the Life Skills Profile (LSP) falls into that category). Functional outcomes may be correlated with clinical outcomes but may also be independent of them eg people with mental illness may have residual symptoms but be able to manage them and function well in other areas. ‘Personal outcomes’ are usually measured by identifying with the consumer personal issues, goals and needs, and assessing at regular intervals if these have been met (eg through identifying them in the Individual Service Plan (ISP) which is reviewed at regular intervals). Quality of Life scales have been used to measure personal satisfaction and wellness. More recent ‘recovery’ outcome measures developed by consumers have much in common with this idea. The categories are not mutually exclusive since acquiring some functional skills may assist the consumers to meet their goals. We will return to these distinctions with Stedman et al later. Key text books also include chapters on the conceptual underpinnings of each outcome tool and on the domains of outcome (see Resources). These categories help to simplify where NGOs might focus their effort to measure domains of relevance to their organisations.

Australian policy reviews and evaluations of RCOM systems

The first National Mental Health Strategy commissioned large concurrent studies to systematically review health outcome related literature and to field trial and narrow the choices of published outcome tools for routine use. The work began with a wide-ranging but not comprehensive appraisal of outcome measures (Andrews et al 1994) for suitability to the Australian clinical service context. They consulted the field, consumer and carer organisations. They put for considerable debate, the conceptual underpinnings of the tools themselves and subjected them to consumer reappraisal of the adequacy of the concepts, focus and orientation of the tools.

In a later report, Stedman and colleagues (1997) retraces the steps of Andrew’s foundation document and notes the salient strategic findings. Of the numerous potential domains on which to focus, consumers identified the following in order of priority:

- measures of ‘disability’ and ‘quality of life’;
- measures of ‘satisfaction with service’; and
- measures of ‘symptoms’.

‘Collaborative interviews between consumers and workers’ was reportedly the preferred method for collecting outcome data. The assessment of service efficacy was the most important use of these data. Then the data should inform progress of care planning, then inform decisions about service funding. Half the professionals responding were experienced in applying some sort of outcome tools. The authors recommended nation-wide piloting at 20-40 sites for the selected measures. The characteristics of preferred measures were identified as needing to be:

- brief;
- low cost;
- multi-dimensional measures;
- require minimal training to be used; and
- require minimal training for administration, interpretation and scoring.

The nominated measures were:

- BASIS-32;
- Mental Health Inventory;
- The Medical Outcomes Study (MOS);
- SF-36 – Short Form Survey 36;
- Health of the Nation Outcome Scale (HoNOS);
- Life Skills Profile; and
- Role Functioning Scale.

The report covered the time needed to use the tools, the feasibility of use, the purpose of the measures and the relative merits of measures for their psychometric properties were reported. The treatment context of undertaking outcome measurement is made clear:

> *'The repeated measurement of diagnoses, symptoms, disability and risk factors using standardised measures is regarded as likely to improve treatment as well as providing the information necessary for identifying the outcome of treatment. Measurement, provided it does not detract from treatment time, does not interfere with treatment' (Stedman et al summary of Andrews et al 1994: 109).*

This highlights a) the uncertainty of diagnosis, often until after the outcome is achieved when treating mental disorders, but also b) the most important caution: that outcome measurement systems must be practical and non intrusive to workers' time to spend with consumers. The same caution applies to NGOs in that they are resource-scarce organisations with often pressured case demands serving often diverse consumer groups for long term life skills, not short term 'treatment'.

Stedman continues: there are problems with attribution. Andrews and colleagues had reported that the change in health can be presumed attributable to treatment in routine clinical practice, but 'not considered 'evidence' of the efficacy of a treatment or the efficacy of a clinic or service'. Disability data are of interest to administrators since they demonstrate the burden of disease and disability; the authors suggest that changes in these measures can form a performance indicator for individual clinics and clinicians. That is, the data are a crude input to overall questions about service efficacy and effectiveness but service evaluation should not use RCOM alone.

Stedman and colleagues (1997) then performed the field trials as recommended by Andrews et al. This QLD University team aimed to assess which measures were most feasible to use routinely in clinical practice for schizophrenia, mood disorders and anxiety disorders. They invited medical not multidisciplinary teams to participate. Three settings, being 65 service providers and 183 consumers, were included in the trials in general practice, private psychiatry and public psychiatry (Stedman 1997). Consumers used BASIS-32, MHI or SF 36. Service providers completed HoNOS, LSP and RFS. Additional measures were taken of illness severity and disability to see if the measures of routine use were adequately sensitive. Focus groups were also used. Key findings were:

- Participants supported the use of the tools.
- There is need for brevity, simplicity, comprehensiveness of what is measured.
- Measures are not the issue, the adequacy of the clinical processes of assessment and the process of outcome assessment did matter to consumers.
- Attribution of the change in the consumer being due to the intervention was approximate or an estimate, not an absolute.
- Was there adequate purpose to outcome measurement on a routine basis?
- Standardised training is required for the administration of measures.
- Privacy.
- Resources were needed to apply systems of outcome measurement.
- Consumers wanted the tools to directly measure satisfaction with services which was not a characteristic of the tools. Others reported that personal outcomes are different to their view of the service effectiveness.
- RCOM was considered feasible. Feasibility was closely related to views about the worth of doing RCOM.
- Measures appeared to indicate more illness severity for people with mood disorders using private psychiatry, consistent with expectations. This shows the utility of data for comparing the needs of consumers in different settings.
- RCOM data needs to be an integral component of an effective clinical information system.
- Outcome measurement should be considered a goal in itself.
- There remains need for more applied research into service effectiveness and the dimensions of consumer outcome.
- Consumers and professionals assessed needs differently: there was poor convergence between consumer and professional assessments. This shows how important it is for professionals to be informed by consumer views of their needs and priorities.
- The measures be considered as a pool of measures, choice depending upon the needs of consumers and the focus of services.
- Finally, the report concluded “There should be a shift towards discussion of the needs of local and regional services; and how data collected at the grass roots level can be meaningfully translated into information that is relevant and useful to higher levels of management in mental health”.

Stedman and colleagues (1997) refined what we know about the choice of measures. Their Table A17 (p.100) gives an organisational guide to all the considerations necessary for implementing RCOM and many of these hold for NGOs. Finally, they report RCOM is part of a process of change in mental health systems, suggestive of an attitude toward it, not as an add-on, but as fundamental to reform. Accordingly, these foundational documents, while not including NGOs, remain informative about cautions, utility and practicalities. The NGO task is translation of these findings into the service contexts of NGO settings. Neither report ruled out the use of the recommended measures with additional measures of interest.

Following Stedman's team, Pirkis et al (1999) reviewed all the methods available to mental health systems for quality management in, *Measuring Quality in Australian Mental Health Services*. Of RCOM they note six contingencies for utility:

- mental health outcomes are complex – about things other than symptoms, subtle factors difficult to operationalise such as making and sustaining relationships. Developing measures is thus complex;
- outcomes are long term in nature, improvements not being absolute;
- different outcomes are different to different stakeholders (consumers may value satisfaction, carers may value functioning, clinicians may value reduced symptoms);
- not all outcome is modifiable, improvement may be small for some consumers;
- outcomes need to be case mix adjusted or corrected for different types of clients which enables one to determine if the change is due to client or service provider factors; and
- outcomes may not be due to the intervention so comparison with similar services or with groups who did not get the service is also needed.

This is useful background on several dimensions of quality improvement approaches and their fit with each other. The report's literature review notes a meta-analysis by Lambert and colleagues (1996): it reports on 348 outcome studies that concluded that of 1400 outcome tools, the majority failed appraisal tests giving rise to new measures being developed, such as the HoNOS (Wing et al 1998).

Routine outcome measurement is now part of State and Territory funding agreements with the Commonwealth and Australia's experience in implementing RCOM has received international acclaim. The policy framework for this development had input from NGOs and consumer and carer opinion leaders. But RCOM has not been an overnight development. It required national data agreements (states agreeing on what should be collected or 'minimum data sets'), significant resources, a computerised workforce, coordination infrastructure and leadership. Pirkis and colleagues (2005) provide an updated appraisal of what has so far been achieved:

> *‘Australia has made an impressive start to nationally implementing routine outcome measurement in mental health services although it still has a long way to go. All States and Territories have established data collection systems, although some are more streamlined than others. Significant numbers of clinicians and managers have been trained in the use of routine outcome measures, and thought is now being given to ongoing training strategies. Outcome measurement is now occurring on the ground….Having said this, there is considerable variability regarding data coverage, completeness and compliance. To date, reporting of outcome data has largely been limited to reports profiling individual consumers and or aggregate reports that focus on compliance….States have began to turn their attention to producing aggregate reports of consumers by clinician, team or service’.*

Pirkis’s team also reports that for outcome measurement systems to be sustained requires ongoing training due to workforce turnover. Being mandated in the public sector, did not guarantee uptake by staff and not all consumers agree to complete measures (Pirkis et al, 2005a).

QLD Health’s “Beyond Outcomes State Forum” on outcome measurement report from workers directly, how they view the benefits in a rehabilitation and extended treatment setting in Townsville (Dixon & Hunt 2005):

- Outcome measurement is incorporated into clinical reviews.
- It is used as a team to achieve consensus.
- It is client focused not clinical activity focused.
- Gives breadth to the client.
- Links directly to client’s specific rehab goals.
- Graphic view of progress can be generated for clinician and client.
- It allows client to talk about their illness.
- Highlights or ‘frames’ staff and client perception.
- Encourages reflection within a framework.
- Focuses staff to develop strategies.
- Need for the future is to aggregate data to direct program planning.
- Strategies for motivating more participation.
- Need for coordinators to drive collection of quality information.

In New Zealand, a system similar to MHOAT has been introduced called MH-Smart (The Mental Health Standard Measures of Assessment and Recovery Initiative). The HoNOS is the main instrument used. NGOs are only just starting to tackle the task of measuring outcomes.

Acceptability of RCOM to workforces

As discussed in the earlier chapter psychiatrists in Australia and elsewhere have mixed views about using outcome tools and data in practice. This is consistent with psychiatrists being difficult to engage in quality improvement more generally which is well reported in the quality management literature. In a study of attitudes from different disciplines to routine outcomes data collection in child and adolescent mental health services (Huffman et al 2004) psychiatrists did approve of the system, but less so than other disciplines. It was reported that once the utility of systematic clinical data collection is shown, agreement is more likely. It is also more likely to occur in an organisational culture in which treatment progress and outcome measurement is integral to clinical work. It must not be made burdensome. Staff who perceive it be a burden are unlikely to participate.

Cochrane Systematic Reviews on utility of RCOM

Gilbody, House and Sheldon (2003) report a Cochrane Review, ‘Outcome measures and needs assessment tools for schizophrenia and related disorders’. They search for evidence that supports the recent trend in health systems in RCOM and needs assessment tools to see if the feedback such data provides improves the management and outcome of patients. It includes data to 2002. RCTs of RCOM systems providing feedback on care were compared to standard care. No RCTs were found. One unpublished trial and an ongoing one were identified. They conclude: ‘The routine use of outcome measures and needs assessments is as yet, unsupported by high quality evidence of clinical and cost effectiveness’.

Gilbody, House and Sheldon (2001) did an earlier systematic review to establish if routinely administered questionnaires for depression and anxiety in non-psychiatric settings could be helpful to detecting, managing and improving the outcomes of mood disorders. RCTs included in the review were those where screening results were feedback to doctors in primary care and hospitals. Nine studies were included and meta-analysis pooled findings for four studies (2457 consumers). Feedback about missed cases led to better detection, but did not change primary care interventions so the effect on patient outcome was not achieved. The authors concluded that the use of these screening tools in primary care is common but a costly exercise and that little evidence shows that it is of benefit in improving psychosocial outcomes in non-psychiatric settings. This is an important caution that workforces must have the skills to interpret feedback and to change their practice toward interventions they have confidence to deliver. However, we are again unable to generalise these findings to NGOs in the Australian context.

Other data on the utility of measures and of RCOM in mental health

Pirkis and colleagues (2005,b) recently reported a review of the psychometric properties of HoNOS family of measures given that they are in wide use in mental health services and since that tools were developed to resolve some of the deficiencies of other tools. The HoNOS was shown to be appropriate for routinely monitoring outcomes in clinical settings. This no doubt assists worker confidence in participating.

Trauer (2004) in Australia reports on how routine outcome measures used in a hospital consultation liaison psychiatry (C-L) service over 3 years. He compared C-L client outcomes and characteristics with those in ambulatory and inpatient mental health settings in the same hospital. This revealed previously unknown data about C-L patients' illness severity and outcomes. We include this as an example of how RCOM measurement has been applied where not mandated and given that it describes how it clarifies the population of consumers being assisted. The C-L assessments were conducted in the general hospital or in the emergency care centre. Mean HoNOS scores were compared between these settings with the acute psychiatric admission unit. Combined with local activity statistics the study confirmed patients' differences were significant in all by 2 areas, depression and 'other psychological problems'. The emergency centre had higher rates of aggression, self harm, substance use, hallucinations, relationship problems, accommodation problems, relationship problems and occupational/leisure problems than the general hospital. Cognitive and physical problems were higher in the general hospital. Most common diagnoses in these settings were mood disorders. The emergency centre and the psychiatric admission unit patients were similar. HoNOS had face validity in all settings. The author reports that the information enabled a range of management decisions to be made on the basis of a clearer understanding of patient problems identified. The authors propose a database be established to enable the general hospital to continue to use RCOM of patients presenting with mental health issues and problems.

Acceptability of RCOM to consumers

The oldest example of routine state-wide outcome measurement in mental health was in two US states (Tennessee and Georgia) published in 1984 (McPheeters 1984), 10 years prior to Australian policy interest and **now 22 years ago**. RCOM is therefore not new technology. It was voluntarily applied in six community mental health programs using the Role Functioning Scale and tied to the quality assurance of services. Tennessee used the Quality of Life Questionnaire and the Program Impact Monitoring System. Both services had successes and challenges which are reflected in more recent literature and guidance on how to operationalise RCOM.

To begin our discussion of consumers as the key stakeholders of importance, we again refer to Stedman et al (1997:9) who made the point that outcome measurement falls within the National Standards for Mental Health Services, ‘That consumers and their carers receive a comprehensive, timely and accurate assessment and a regular review of progress’. These Standards have consumer leader input and endorsement.

Professor Trauer (2004) in Australia reviewed the literature on the acceptability of consumer outcome measurement in his paper on the consumer and service determinants of **completion of consumer self-rated outcome** measures. He appraised 22,928 records of consumer assessment from 4 public community mental health organisations in Victoria. Professor Trauer assessed completion rates for 6114 patients with any assessment data. Of these, 3351 had data at review of their care (including the HoNOS done by clinicians) but 66% of patients did not complete a BASIS. Organisational culture had a stronger relationship to the completion of measures by consumers than did consumer characteristics. Just over half the 220 clinicians (predominantly nurses and allied health) had no consumer BASIS completed by consumers. Completion requires that consumers be offered the opportunity to complete a self-assessment. He found that where clinicians offered consumers the tools (better performing agencies) around 38.8% of consumers with psychosis completed it, 30.2% of those with mood disorder did so, 29% for personality disorder did so and lower rates were found for those with substance use, anxiety or organic disorders. Across the sample, 32.4% of consumers used the tools. One organisation had been using outcome measures since 1999.

His literature account reported studies by Greist et al that found most patients **liked computer interviews** and found it less embarrassing; a study by Epstein et al that found those in the general population reported more mental health issues using a computer-assisted self-interview than with interviewer-administered or paper based assessment. In cardiac samples 82% of patients preferred computer and 89% preferred to do it in future without technical assistance. Literature had previously found that those with acute psychosis, organic conditions, intoxicated clients and those with literacy problems will have difficulty completing self assessment and health outcome tools. He refers to other authors who found that younger clients are more likely to agree to participate. It was suggested that computer administration is a way to increase the participation rate by consumers when using self-rated measures. Finally, he reports literature where if outcome measurement is managed skilfully (with the clinician discussing the findings with consumers) consumers feel more satisfied with care.

Trauer and Callaly (2002) had previously reported that consumers who **are treated involuntarily** in Australian mental health services are less likely to complete measures. Legal status of patients is imposed due to lack of compliance with treatment so it is not surprising that the same patients may decline to participate in treatment processes.

In Australia's first **National Youth Suicide Prevention Strategy** (1996-2000) a number of evaluation reports from 33 demonstration programs were synthesised in a series of summative evaluation reports (Mitchell 2000). Many projects identified that young people participated well in completing visual analogue scales of suicide risk, depression, other mental health symptom scales and other outcome measures. The settings included tertiary clinical services for mood disorder, psychosis, psychosis and substance use, general practice suicide prevention programs and NGOs. These measures were administered for up to a 3-year period for some evaluations. The Strategy advocated that evaluation capacity building be fostered in all human services working with young people at risk for suicide and in mental health services.

Utility of RCOM in Non Government Organisations

The **consumer 'recovery' movement** has advocated RCOM. RCOM has been interpreted by some authors as one more strategy for consumer participation, empowerment and collaboration in care planning. In this sense RCOM becomes a process of care and an intervention. Others suggest (like 'recovery' itself) RCOM is not an add-on to existing services, but is a way to fundamentally change or focus mental health systems.

Consumers in many parts of the world have contributed to the development of outcome measurement work and have instigated the development of measures suggestive of agreement with the concept of RCOM in general as a component of service accountability to consumers. In the United Kingdom, **the Mental Health Association, MINDS UK** and their offices in Glasgow and Bristol participated in or initiated the development of the **Avon Mental Health Measure (AVON)**. It was developed with input by Bristol University in 1996 (its origin is difficult to find full text of, but it is believed to be first published by Markovitz P, *The Avon Mental Health Measure*, Bristol, MINDS Changing Minds Program). The MINDS Changing Minds project aimed to combat stigma and the tool was developed by NGO consumers based on the strengths, skills and needs required to combat stigma. It conceptually differs from other tools in this strengths orientation. It was field tested by collaborations of consumers, social workers and psychiatrists. There was consensus among clinicians and service users that both professional and client perspectives are needed in measuring outcomes, and that AVON was the preferred instrument.

Hunter and colleagues (2004) for The Scottish 700 Outcomes Study, compared HoNOS with the AVON and the tool, Outcome of Problems of Users of Services (OPUS) for potential routine use in adult mental health services. They found the AVON was superior in that it detects what service users judge to be most important and is more sensitive than the HoNOS. Content validity and levels of agreement between professionals and service users of three measures was undertaken. While the HoNOS was devised by mental health professionals the AVON was devised by consumers and health professionals in partnership. Measures were used by 700 predominantly long-term users of mental health services and by their key worker and all diagnostic groups were represented. A small sub-sample had repeat testing after 3 months to assess sensitivity to change of the three measures. OPUS detected issues not otherwise picked up by the other two measures and agreement between measures was low. AVON was more likely to detect problems and all measures were sensitive to change. Available information is that the AVON is available through MINDS for free.

A period of three years of field testing the measure followed. By 2001 AVON was the nominated measure by the Scottish Mental Health Reference Group which gave guidance to the Scottish major policy document, *Framework for Mental Health Services in Scotland*. They proposed it in *Needs Assessment for Comprehensive, Local Mental Health Services* as the tool of choice for RCOM in all settings. Needs assessment beyond the individual was also advocated to be done at the population health level. The proposal was that RCOM does not exist without other quality improvement and wider needs-based planning in place. In 2005, the AVON was listed for use nationally in Scotland in *Improving mental health services in Scotland Developing a Strategic Framework for Quality Improvement* (NHS Quality Improvement Scotland 2005). The report says of the AVON (p.9),

> *'although the measurement of outcome for an individual has been a concern for two decades, there is no agreement on how it should be done, especially how the user, carer and professional views should be balanced. A surprising finding from two rounds of assessment…..is that the professional skill and mix of individual mental health teams shows little relationship to the assessed needs of service users; this may be the reason for the lack of availability of psychosocial interventions, despite the evidence base for the importance of such interventions'.*

Along the same lines, Anthony (2000) explores standards and outcomes in the context of a 'recovery oriented service', as a way of encouraging services which have not adopted a recovery orientation, to do so. Anthony identifies consumer outcomes in many different arenas, but does not discuss the use of outcome measures. He recommends that outcomes should be built into the service planning framework for all recovery and rehabilitation services.

In the Australian context, there is emerging debate in mental health conferences (VICSERV Panel: Clarke, O'Hagan, Hocking, Davidson, Jeffs, Meadows, Chong 2004) and the literature about whether or not the **concept of 'recovery' is and need be measurable**. New Zealand consumer leader and researcher, Mary O'Hagan reports: "I think recovery can be measured. I used to measure my own recovery. I used to put a number between 1 and 10 in my diary every night. At the end of the year I would type them up and compare them with the previous year. I knew I was worse this year than last but this was just evidence that confirmed it. I think we get very complicated about evidence" (VICSER 2004:20). Here we are reminded of the distinctions between formal care, informal care and self care and the question of what service users versus service providers should each be responsible for.

In the United States, the National Association of State Mental Health Program Directors have published their argument why there is the need for recovery to be measurable: for accountability, qualitative and quantitative reasons. It explores the value of the Recovery Measurement Tool at the individual level, the Recovery Enhancing Environment Measure, at the Program level, and the Consumer Self-Report Survey at the System level (Onken et al, 2000).

In a similar vein, Australian researchers, Oades and colleagues (2005) from Wollongong University describe 'collaborative recovery' outlining how mental health services might adopt a recovery orientation but with integration of other knowledge bases including evidence-based practice. The article's focus is to assist services to help people with chronic and enduring psychiatric disabilities using a recovery philosophy. The model is a training framework for the reform of existing services, which required the retraining of workforces around recovery principles. It is not a 'model' of recovery nor a system of RCOM. The researchers use the Camberwell Assessment of Needs (CANSAS) to facilitate collaboration between the worker and the consumer on goal setting and for the ongoing monitoring of these. The model departs little from existing understandings of involving consumers in clinical or other decision-making but using consumer focused needs assessment and tailoring these understandings to the reform needed in services. Goal progress can be tracked using a goal attainment index (a percentage of goal attainment that may function independently to standard problem and symptom distress measures). A more comprehensive picture about changes the consumer is experiencing emerges. The team is working with public and NGO mental health services in three States to evaluate this model. It should be noted that other studies compare the AVON with the CAN and find AVON superior in some aspects of consumer need.

Victorian experience

In Victoria, there are three mandated tools and PDRSS agencies may choose one of the three (LSP, HoNOS or BASIS -32) being tools within Stedman's 'pool' to be applied routinely for funded programs. A brief guide-book for the selection of tools is provided by La Trobe University, called, '*Improving Services through Consumer Population Outcome Measurement in PDRSS*'. The publication does not have an author or date. It discusses what to do with collected data and interpretation issues: ‘The major analytic potential of consumer outcomes data arises when they can be compared with outcomes for other populations of PDRSS consumers or with the same population at different points in time. Comparisons of this type are most useful for helping to target program and service areas that are likely to benefit from continuous improvement activities’ (La Trobe University p.15).

Vanos and Cahill (2002) in an unpublished conference paper, report on implementing BASIS-32 and **Camberwell Assessment of Need** (CAN) into their non-government organisations in Victoria. The tools were applied in three programs, a Day Program and a Home Based Outreach Support program of Neami and a residential program of Mental Illness Fellowship. Neami commenced the BASIS in April 2001 and CAN in September 2001. The BASIS repeat measure was done a year later and paper based forms were used. Neami had a Quality Improvement Manager at the time assisting implementation. Challenges for implementation were setting an agreed time between worker and consumer to complete the forms in a structured way. A fit had to be found with the review schedule of client Individual Service Plans. Flexibility on not completing some items was needed and consumers could opt in or out. Neami found **87% of clients** chose to complete the BASIS and 93% chose to complete the CAN. Benefits included:

- Forcing workers to offer a structured interview meant issues were raised not otherwise likely to be brought up by a consumer: an example is “a person may present well in terms of self care, however without asking we may not have known that it takes her four showers and changes of clothes to get that way each morning”.
- The organisations were able to analyse what different client groups need with flow on benefits to the organisation in planning, seeking additional funds, networking, employment of new staff, and improved professional development.
- Mental Illness Fellowship identified that the system enabled them to create a research agenda and better give consumers a voice to improve their lives.
- In their 24 hour staffed residential which is jointly managed with the Area Mental Health Service, the joint care plans were enriched. CAN was used within 6 weeks of service entry.
- The use of tools strengthened the working partnership between the NGO and the Area Mental Health Service.

Tobias and Trauer (2003) also describe measuring consumer outcome in Neami, PDRSS service in *New Paradigm.* Neami, a mental health NGO providing community rehabilitation and support, reports using the Behaviour and Symptom Identification Scale (BASIS 32), a consumer self-rated measure. Agency and consumer experience was largely very positive, with 85% of those consumers offered BASIS 32, completing it. It is noted that this participation rate is higher than in public mental health services. The agency involved staff in making the choice to adopt the use of this instrument. It is reported that staff confidence in working with consumers, with a focus on recovery has been improved and consumers have reported that they could see personal benefit in completing it. The same topic is reported later in peer-reviewed literature as Trauer and Tobias (2004) when the study matured.

No tools or data collection system is established or required by NSW Health for the specialist mental health NGOs it funds. We did not find in the literature examples of any other system required by generalist NGOs in NSW. However NGOs funded under HASI contracts (Chapter 3) are involved in outcome measuring. However, NGO collection and use of outcome data appears embedded into funding systems in the United States and in the UK, in the latter, in relation to the collaborative Trust arrangements for mental health programs.

Blankertz and Cook (1998) argue that psychosocial rehabilitation providers need to adopt the use of outcome measures. They focus on ‘functional outcomes’. They provide a guide to agencies in choosing appropriate measures, identifying issues such as the focus of the measurement system, and the domains covered in outcome measurement. The importance of staff involvement with the process, and ability to gain value from the data, is identified, as is the fact that a feedback loop, to pass on de-identified simple reports to stakeholders, needs to be built into the process.

Elsewhere overseas, one of the well-documented consumer outcome measures is the Toolkit developed by the International Association of Psychosocial Rehabilitation Services (IAPSRS) to assist its members seeking to compete in the managed care environment (Arns et al 2001). The toolkit has a rehabilitation perspective and a recovery focus and has measures valued by consumers’ as well as those identified by intended program goals. It utilises a minimal dataset, is domain-based, and contains demographic data. Its domain includes: employment, educational activity, residential situation. It collects information on financial status, legal involvement, hospitalisation, service satisfaction, perceived quality of life and the person’s sense of mastery. It was piloted in 1995-1997 in 26 agencies in the USA, 875 Toolkits being completed and was found to be useful in detecting changes between assessments in several domains. An analysis of the results showed that the survey could be conceived as consisting of three subscales: Quality of life, Mastery and Program satisfaction. The Toolkit was extensively piloted and revised and has since been used in Ontario, Canada.

Discussion

RCOM is not new. In the past 10 years, internationally, NGOs have both developed and adopted consumer outcome tools for routine use. One tool developed by an NGO (AVON) became the preferred tool in Scotland nationally for all services to apply. These accounts convince that RCOM is acceptable and is useful to many consumer groups and to some NGO workforces and furthermore, RCOM has been proposed both in Australia and internationally, as a mental health system advocacy and reform instrument.

But there is little **evaluative** data, other than descriptions by authors of their agency's agreement with routine outcome monitoring. Impacts from RCOM on outcomes of care and its value as a quality improvement technology is only just emerging. There appears to be improved quality in consumer-worker interactions from the use of these tools is done with skill so consumers feel more listened to and involved in their care. RCOM has also been a lever for advocacy for funding and for the adoption of a recovery orientation in services. The data services gather have been used internally to understand the impact of services offered and to refine or redesign the services.

RCOM is proposed in the literature as a tool for major reform. The extent to which NGOs require major reform at all, or with any consensus about particular directions for reform (along the lines that there is consensus that reform is needed by public sector mental health services), is a point for further discussion and research. NGOs may be acceptable to consumers just as they are. NGO service approaches already reflect the sort of services and philosophies of care consumers reportedly want to receive (Penrose-Wall & Bateman 2006) and to participate in. However NGOs cannot currently demonstrate either satisfaction or consumer dissatisfaction, nor other outcomes from using those services unless NGOs have data about their organisations, service users and participants, programs and outcomes.

Of note for considering the feasibility of RCOM in NGOs is that at least one NGO has reported completion of outcome measures by consumers three times that of public sector mental health services in the same State. Staff had high willingness to offer outcome tools for consumer use. NGOs may participate well voluntarily with seed funds and incentives to do so in-keeping with their need to be sustainable through being highly relevant to and acceptable to consumers and communities in need.

Outcome measurement is a sizable and long-term commitment. Available information suggests NGOs *must* develop workforces with 'outcomes of care cultures' willing to orient themselves to a health outcomes culture, rather than an activity culture, if they are to remain relevant to consumers and communities and if they are to retain public funding support. Finally, systems of electronic storage of outcome data is intended to be a **tool for services to use** to be able to make sense of the data themselves by engaging with it, rather than generating data for use only by a distant expert (or by funders). The literature suggests that introducing an outcome measurement system provides a major positive capacity building not only at the worker-consumer level, but at subsequent organisational and sector levels.

Model of care questions remain regarding the extent to which NGO programs in NSW lend themselves to RCOM and could become more evidence-based and effective by using RCOM. At present around half are unlikely to use it due to having a population focus rather than individually focused programs (and we do not suggest that a population focus ever be discouraged). Ultimately, workforce characteristics and needs must first be known to tailor outcome monitoring systems to agency capacities and roles.

Successful RCOM systems were shown to have been introduced after sound understanding was available of the workforce, the culture, the practice context of the organisation, and with a fit to existing quality frameworks. Sustained leadership and feedback of results must be provided to workers. Financial incentives have been shown to generate uptake of outcome monitoring in Australian General Practice and infrastructures to support evaluation capacity building through 126 Divisions. To achieve cultural change toward a health outcome approach by the 144 NGOs in NSW similarly requires coordination and infrastructure support. While there is little published research on NGO experience implementing RCOM systems from scratch, there is sufficient information and expertise from other sectors and there is need to quality assure and evaluate its introduction.

Conclusion

There is considerable evidence from consumer consultations that outcome measurement is acceptable to consumers and has utility in the worker-consumer interaction to improve the care process and relationship. There are cautions and also encouragement from the experiences of introducing RCOM in other health care systems and settings. The biggest caution in not burdening agencies with paper work that can compromise caring relationships and worker responsiveness to consumers. It is too early to know its ultimate contribution to quality management in human services. The literature points to the need for specific inputs using Technical Papers, training, leadership strategies or other expert supports. Finally, organisations currently participating in RCOM should be encouraged and supported to obtain evaluation results from these collections. Coordination of the data state-wide, by NGOs in agreement with each other, is feasible as indicated in the Australian Divisions of General Practice and VICSERV examples. Finally, the CANSAS and Avon have data supporting their sensitivity in similar NGO service contexts to those in NSW.

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. It 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 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.

5

CHOICES OF OUTCOME MEASURES

Introduction

Here we summarise available measures already in use in public and NGO mental health settings and suggest a framework for guiding NGOs toward a choice of outcome tool. As stated in the Introduction, we have not tested the merits of the tools using the methods of formal appraisal proposed in the literature. A technical paper may be required to argue through for members the merits of a narrowed set of choices between the hundreds or thousands of published outcome tools. Here we only introduce that process and recommend a common preliminary tool (CAN or CANSAS) be adopted by NSW NGOs for pilot use.

The table overleaf summarises what we extracted from the literature about the measures: the time taken to administer it by or with the consumer, if it had been used in at least one NGO (in Australia or similar international counterparts where we found reports appraising its usefulness), if it is used in MHOAT in NSW and its description.

It should be recalled from earlier chapters that NGOs considering outcome measures will ideally select more than one measure for each consumer and they should be short and not burdensome.

Principles for use when selecting outcome measures then follow as do 'Resources' which lists key texts and websites which profile each tool in detail.

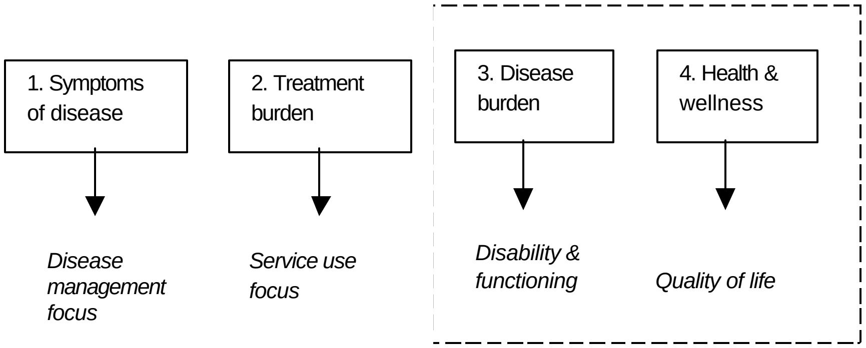
Choices of routine consumer health outcome measures

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 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 **this NGO reported** not finding 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

				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 by NGOs



Recall the ‘domains of outcome measures’ reported in the literature review and repeated above: this paper argued that NGOs in NSW are distinct in ‘who they are’ as the independent sector, but also that they perform some distinct roles (albeit with some overlap with public mental health services) (or the ‘what they do’ perspective). 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.

Many NGOs on the other hand, add value, by assisting consumers to make the most of life while living with or overcoming a mental illness or psychiatric disability. NGOs promote health and relationship wellbeing despite a person having a mental health problem that may recur. NGOs also provide social networks, opportunities for consumers to engage in community events, groups and programs for enjoyment and enrichment, without which, life in the community for some people with mental illness may be more lonely and without much meaning. 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. That being so, if an NGO is housing people it will still have an interest to know how the person is going regarding the severity or stability of symptoms since this will involve supervision and staffing questions to ensure safety and support for the consumer. Multidimensional measures have thus been advocated for routine use. We suggest multidimensional measures are ideal for NGOs regardless of the fact that NGOs do not have a ‘treatment’ role. Having said that, measures with a focus on domains 3 and 4 above, will best reflect the activities of the NGO and will therefore be more sensitive as service evaluation tools for the NGO's purposes.

We have considered a number of published principles for selecting outcome measures. Those proposed by the Outcomes Roundtable (Smith et al 1997) include:

- Select measures appropriate to the questions to be answered by the organisation
- Select measures with demonstrated validity and reliability and sensitivity to change over time
- Select measures that always include the consumer perspective (choose at least one that is completed by or with consumers)
- Select measures that don't burden and are adaptable to different health care systems
- Select measures that include general health and mental health status
- Select measures that include consumers' evaluation of treatment and outcomes
- Select measures that include generic and disorder-specific information
- Select measures that include areas of personal functioning affected by the disorder
- Try to examine outcomes for those persons who leave programs early

The remaining 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 FIELD TESTED MEASURES	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 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).

Discussion

The tools in the table have been judged by outcome researchers or by State health systems in Australia or internationally as reliable and appropriate for routine use to elicit consumer needs and outcomes when individually-oriented programs are used by consumers. They have been used sufficiently elsewhere to offer some comparison data. In some cases these data are being collected in Australia. The list is not meant to suggest other tools are not potentially helpful to NGOs, merely that a separate research process is required to report on the utility of a wider set of measures. This is particularly so since the growth in consumer ‘recovery’ measures and how we conceptualise those domains relative to NGO psychosocial interventions needs consideration. There are also many measures of social support understood through several contested theoretical perspectives. Finally, there are many measures of family/carer burden and needs which may have a place in NGOs.

The AVON appears worthy of considerable attention because, like the CAN it measures needs met and unmet but it is NGO and consumer-developed and has been adopted nationally in Scotland for use by all mental health services.

Users of tools need to take into account the different purposes served by outcome measures by different agencies that consumers may use for mental health care. It is important for NGOs to be aware that different tools and approaches have different strengths and weaknesses. A number of questions need to be asked such as:

- how sensitive to change is this tool and this approach;
- what are consumers’ views of it;
- what is the process for using it (where, when, on paper, on computer);

- how often can it be used with the same person without having a 'coaching' effect; (and without boring the consumer)
- (most importantly), what is the purpose of using the tool?

Quality managing how RCOM is applied

There are instances where a tool may be administered inappropriately, for example where consumers' life circumstances are in a state of flux. For consumers who are not literate in English, barriers exist for them in participating in an exercise dependent on reading ability and comprehension of written English. Questions may be narrowly focused (in a cultural sense) and may not reflect the diversity of backgrounds of the population being measured.

Different tools may be needed if we are comparing the outcome for a *particular consumer* over time than if we need to collect information at a *particular time* about a group of consumers. For example, the Life Skills Profile when first constructed could distinguish between groups of people in institutions and groups of people living in the community but a number of MHCC members thought it is not particularly sensitive to changes over time for individual consumers living in the community.

Integration between systems of care

A consumer may use more than one service type (e.g. supported accommodation and employment services) and some consumers move across a number of similar services across time. Many service users also use clinical services provided in the public or private sector, and some use generalist NGOs (such as HACC funded ones) for a range of services. It may be useful to have some agreement across services about the use of at least some tools and processes. NGOs and public sector mental health services could agree on at least one common tool being in use, but should avoid consumers being exposed to the tool in both organisations simultaneously. Or they could agree to share data about consumer need or progress where the consumer agrees and uses both services.

Such an approach is used in NSW elsewhere, for example, the CIARR is used across all HACC services. In Victoria, the use of Service Coordination Tool is mandated across all community health and generalist community services.

Generalist NGOs and those providing resilience and prevention

There is unmet mental health need remaining for persons already using individually-oriented NGO specialist mental health programs (Bateman & Johnson 2000). The low prevalence survey of 3000 persons within the National Survey of Mental Health and Wellbeing also reported those with psychosis already using mental health services to have unacceptable levels of loneliness, isolation, poverty, homelessness, depression, relationship loss and current suicidal thoughts and plans — in short, they are the most disadvantaged and vulnerable of Australian citizens (Jablenski 1999). There is scope for screening of ongoing health status and risk factors (including behavioural) in those we already know have a serious mental disorder no matter their level of engagement with specialist mental health programs. Separate attention needs to be given to the question **of opportunistic screening** for this population which might be done by generalist NGO programs and NGOs that provide prevention and resilience programs who target populations and not only individuals.

Further, there is a larger group of persons with unmet need in the middle ground. This is a group identified by GPs as needing an ‘intermediate care’ response, with needs not addressed in primary or specialist mental health services and with needs unable to be met by GPs. They may not have psychosis, but mood, personality, somatic and substance use problems or emotional and social needs. Preventing worsening of ill health is highly relevant. Targeted population screening may be indicated but this requires further thought, research, training and program development. Again workforce characteristics will determine this along with discussion and feedback from readers of this paper. Screening tools cover a wide area, principally those validated for primary care or for administration by non medical workforces should be considered were this direction to be pursued.

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.

6 IMPLEMENTATION

Our goal is to further humanise services by sensitising staff more to consumer needs and preferences. It is also consistent with NGO commitment to enable persons experiencing mental illness and disability to be emancipated through their wider human capacities and networks from only 'service provision' ways of thinking about their needs, talents and rights.

This chapter sums up. Is there justification for the adoption of RCOM by NGOs who find it relevant? The vision we have elaborated can be counterbalanced by arguments against it. Further, alternatives to RCOM for quality improvement exist (RED, screening programs, process of care outcomes etc). We ask whose job it is to support a system of health outcome introduction (government or the industry), outline feasibility issues for its support and map potential objections and next steps. Australia nominated preferred measures for the specialist mental health sector in 1994 and in 2003 for the general practice sector. The most common tools are questionnaires and rating scales, which have been researched and developed such that they have good psychometric characteristics (sees Appendices). We think it is time for NSW NGOs to consider their relationship to what has been called a 'mental health outcome movement'.

Potential challenges and objections

The key potential objection to RCOM is not an insignificant one. It is an objection to, misunderstanding about or ambivalence of attitude toward evidence-based programming or practice (EBP). This objection may play out at several levels. A fundamental objection within this is that EBP critics challenge the assumption that more structured, documented care equals 'better care', especially in high-pressure low-resourced settings. Doctors have particularly argued about this assumption in general practice arguing that the 'art' of medicine is as important as the ‘science’. NGOs may have difficulty finding a fit with this evidence-based programming paradigm since their traditional practices or intuitive care planning has found good community acceptance often leading to global mental health movements and sustainable programs. Yet the latter traditional program approaches still have a place: what happens in local community and the needs detected there by NGOs (say through community needs analysis as shown in Figure 1) will be detected more rapidly by an NGO than what is noted in research as needing action at a wider level of recognised public health need. Community organisations can respond to local needs but many do not do systematic needs based planning. Furthermore, There is a great deal more programming happening on the ground than ever is written about in the literature and learning from, and applying this practical experience retains value. However where there is compelling documented evidence about effective program models, evidence based programs should be integrated into existing programs where possible to strengthen program impacts.

A more serious objection, and one that has merit, is that once programs become ‘structured’ in order to control program processes and measure the impacts and outcomes of programs, organisational cultures become ‘exclusive’ and excluding. Obsessed with ‘demonstrating outcomes’ they tighten entry to their programs to individuals that fit the program, rather than the NGO responding to individuals with diverse and complex needs in flexible and a humane manner. Professor Webster alludes to this problem in the Key Messages page quotation, ‘outcome measurement is not the main game, helping people is the main game……’. NGOs have had value by being flexible and willing to respond to complex needs in inclusive ways. Accordingly, the introduction of structured care processes and health outcome monitoring must safeguard service access and organisational cultures of inclusion. Other quality improvement measures are needed to ensure the reasonableness with which health outcome monitoring is implemented.

When working with individuals however, RCOM offers a technology for being precise about planning care for individuals, as opposed to organisations planning how they respond to a whole community or population. By feeding back the results, and modifying the approach to improve outcomes, individual needs have more chance of being recognised and satisfied.

There is a vast literature on objections to or the limits of evidence-based medicine, evidence-based public policy, evidence-based public health, social work, nursing and other disciplines from which NGOs might consider their organisations’ position. The most often put objection is that too much of a deal is made of ‘evidence-based practice’ in light of little research being available in particular areas, a claim relevant to mental health NGOs performing psychosocial rehabilitation services. On the other hand, evidence-based practice that keeps perspective of its limits, can judiciously begin to fill knowledge gaps by valuing the use of available information and data from practice ***and*** from research. We end up with practice-based research and research-based practice. Organisations are referred to the Canadian Association for Mental Health 'Framework for Support' (Trainor et al 2004) to consider this objection in light of their synthesis of the knowledges and strategic considerations.

Operational challenges for organisations

There are a number of issues for organisations in tackling the tasks of RCOM:

- Size: smaller NGOs have fewer personnel and technical resources to plan and implement the measurement of consumer outcomes. Their task is simpler: fewer staff to train, fewer consumers to assess, fewer stakeholders to consult, fewer activities and a culture that may be easier to re-orient. But there are economies of scale in setting up data gathering and analysis processes, and small organisations miss out here. Some NGOs may wish to buddy with others to administer a RCOM program.
- Cost: the likely costs associated with implementing outcome measurement include the cost of training (including travel and accommodation costs for rural providers), cost of replacing support staff while they attend training, cost of the time spent carrying out the necessary assessments, and infrastructure costs such as having electronic systems to collect and analyse the data.
- Workforce characteristics: some NGO agencies employ staff with professional qualifications in human services while others have a mixture of professionally qualified staff and those with extensive or limited experience in personal care. Most agencies rely to some extent on casual staff and many experience high staff turnover. These characteristics are likely to impact on the staff interest, agreement with and compliance with new assessment formats and new technology. Compliance including as a result of high staff turnover has been a key difficulty in the implementation of routine health outcome measurement in government mental health services nationally (Pirkis et al, 2005).
- IT sophistication: while the administration of outcome measures can be paper based, the storage, analysis, interpretation and transition of information collected by those tools is best handled electronically. Agencies differ in their access to IT, IT support and computerised workforces.
- Different funding and reporting requirements of NGOs: different funding programs (SAAP, HACC, DSP, Health) have different funding and reporting requirements. Even within mental health funding there are different practices in different Area Mental Health Services.

To tackle those tasks agencies need support. They also need feedback on the strategies they use and they must see some benefit to them in generating data and data analyses. Information from those analyses must be circulated and the sector must be given opportunities to comment on any results. The sector must also be given opportunities to alter or reject any aspects of data collection that proves unfruitful but this would need to be done well after systems have matured to a degree that the utility has been able to be appraised properly. Coordination and leadership are vital.

Tasks for organisations

Re-orienting an individual agency to incorporate at least some outcome measurement into the practice of the organisation may involve one or more of the following:

1. Training Board and Management on the issues around consumer outcomes and existing government policies in this regard.
2. Consulting with stakeholders: association members, staff, consumers, carers, advocates, local organisations, Area Mental Health on issues around consumer outcomes.
3. Identifying service evaluation and the measurement of consumer outcomes as important activities in strategic and work plans.
4. Identifying consumer outcome data and measures already in use in the organisation or mandated by a funding body or previously agreed to by the organisation. Organisations may already be doing more than they realise. This is the starting point for further development in this area.
5. Identifying with their stakeholders those consumer outcomes that they wish to evaluate in addition to any mandatory collections
6. Establishing the cost of training, new processes (including new technology), and purchasing the skills for the analysis of data.
7. Identifying resources for the task.
8. Motivating staff to understand and use tools as part of their professional practice.
9. Educating consumers about the role and value of measuring outcomes.
10. Modifying work practices and organisational processes to collect and analyse the data.
11. Collecting the data on a regular basis.

12. Analysing and interpreting the data or outsourcing this.

13. Using the information generated by analysis to improve the service.

Renhard (2001) notes that an overarching characteristic for success implicit in the tasks above is *sustained management support* for this way of working. The management of many NSW Mental Health NGOs has already made a commitment to quality improvement and to monitoring consumer outcomes.

The role of government

Renhard (2001) argues that government has a role in providing incentives and support to develop health outcomes and quality improvement cultures. This applies to evaluation and measuring outcomes as much as it does to a broader CQI culture. In the context of the present discussion, the re-orientation of services to a culture of quality improvement, evaluation and the measurement of consumer outcomes must be supported by the NSW Government through the Centre for Mental Health.

Funding of the project which has generated this paper should only be the initial part of the commitment to better quality in NGO mental health services. Support from Government could include:

- IT support, software and IT training;
- Support with privacy considerations; and
- Participation in an expert group to work on the development of uniform data collection system throughout the NGO sector.

The role of research

It is clear from the preceding discussion that research, evaluation (other than outcome measurement) and development are intrinsic to the development of outcome measures which are useful to the consumer and to the organisation assisting that consumer to achieve functional and personal outcomes and quality of life. MHCC members’ experience as providers in the field in using and interpreting data can seed capacity growth toward more formal research, which can in turn contribute to our endeavours as a sector. At the July seminar, members expressed the view that there are real opportunities to foster collaboration and build partnerships between providers and experts in the field, in order to increase the use of good practice in evaluation and to make that practice relevant to everyday provision.

Conclusion

MHOAT is in its 5th year and its implementation is as yet is not fully implemented (Pirkis et al 2005a). The collection of consumer outcome data or of any other evaluation strategy must be used as part of a wider strategy to develop the capacity of the NGO sector, both specialist and generalist to offer better services to consumers with mental illness. Data obtained from the measurement of consumer outcomes should not be used in the development phase of this initiative to make funding decisions about any organisations.

There is now expert experience Australia-wide that MHCC member organisations can draw upon to move the sector toward an outcomes approach making any quality initiative potentially feasible with a step-by-step approach, factoring into plans the unique workforce of mental health specialist and generalist NGOs.

A next step is a short but expert Technical Paper on Consumer Outcome Measures for NSW Mental Health NGOs to formally appraise some measures not included in other Australian reviews. It would address overlap of measures taken for the one consumer (were the consumer to agree) in both settings in the event the consumer is using NGO and clinical mental health services.

MHCC commenced this important work with the assistance of funding by the Centre for Mental Health has but it relies upon member consent and interest to work in these directions.

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RESOURCES

Websites containing information on outcome measurement

Mental Health Resources: Psychiatric Rating Scales:
http://www.library.adelaide.edu.au/guide/med/menthealth/scales.html#G http://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 Editio*n. 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 scales), 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 of health outcome measurement and management. A book review has been published by Barbara Dickey in *Psychiatric Services* (1998). 49: 840-841.

APPENDIX 1: THE NSW NGO DEVELOPMENT STRATEGY

In August 2004 MHCC commenced a three-year NGO Development Strategy funded by the Centre for Mental Health. The Strategy has been initiated with the recognition that services for people with mental illness or disability due to mental illness are delivered by a wide range of organisations both within and outside the mental health sector. The latter include housing and accommodation, criminal justice and the alcohol and other drugs areas. The scope of the Strategy incorporates developing the capacity of both mental health specialist NGOs as well as relevant generalist NGOs whose clients include but are not restricted to those with a mental health problem or need. The Strategy aims to better plan and deliver services to clients with a mental illness or a disability due to mental illness regardless of mental health focus or lack there of that the NGO has.

Specifically, the Strategy aims to:

- increase the capacity of the mental health and generalist NGO organisations to provide services for people affected by mental illness in the community
- encourage improved collaboration and partnerships in service planning and delivery between NGOs and between NGOs and funding bodies
- promote the importance and value of non governmental organisations in assisting people affected by mental illness or a disability due to mental illness.

The Strategy is working in the three areas:

- Training and Workforce Development;
- Quality and Outcomes; and
- Promoting Partnerships.

APPENDIX 2: SOME CHARACTERISTICS OF GOOD OUTCOME MEASURES

1. Standardisation

This refers to uniformity of procedure in administering and interpreting the test or tool. If we are to compare different individuals, the conditions under which we use the tool must be the same for all. For example, the way instructions are given are the same and the test is scored in the same way even if different people administer it. A second aspect of standardisation is the establishment of *norms or* tables of comparison. During the development phase of the tool, it is given to large representative samples of the groups for which it is intended. For example the Life Skills Profile (LSP) has norms for people living in institutions and for people living with mental illness in the community. The tables of comparison (norms) show the average and usually the standard deviation (SD) of the tool. The SD allows the user to determine if a score below or above the average is common or relatively rare i.e., it gives an idea of how the individual is ranked among a sample of people fairly similar in other ways. Norms may need to be established for an Australian context if the tool was developed elsewhere.

2. Reliability

This means consistency and freedom from major errors in measurement. In psychological testing and all other measurement, there are always some errors due to chance fluctuations. A good test reduces the chance of such errors. If the test is meant to measure some permanent or semi-permanent characteristics, the scores obtained on one occasion must be consistent with the score obtained shortly afterwards. For example, if a person is assessed using the test on Tuesday, they must have the same ranking as when they are assessed on Wednesday (provided there has been no catastrophe). On the other hand, for tests meant to measure fluctuations in mood, for example, the error margins are measured differently. The measurement of reliability is quite complex and it is usually expressed as a correlation coefficient. Users should note that changing a tool, shortening it, removing or adding items changes the reliability i.e. the error margins.

3. Validity

Validity is a measure of how accurately a tool measures what it is meant to measure. Validity is measured during test construction by correlating test measures against external criteria. For example, if we had a tool that aimed at predicting success at school we would compare the test results with actual school results and get a measure of how accurate the test is. Validity is established during test construction using validation samples. Once we establish that the validity of a test is high we can use it in practice. Validity is much harder to establish than reliability, especially in the mental health field where there may be difficulties in establishing external criteria.

4. Discriminatory capacity

A test must also allow us to distinguish between individuals. Tests where most individuals' scores are very close to each other are not useful if we need to measure differences between people. A good standardisation usually ensures a ' good spread ' of scores.

5. Capacity to measure change ('sensitivity')

Changes for consumers of psychosocial rehabilitation may be very small initially. An appropriate tool should be able to be very sensitive to those changes, and to be able to measure these reliably. One of the difficulties is that even in the best of tools there are natural fluctuations. If those fluctuations are larger than the 'changes' observed through repeated applications, the change, measured by the service provider, may be deemed 'not significant' because we don't know if it is a change or whether it comes within the error range.

APPENDIX 3: EXAMPLE TOOLS

The layout in the pages overleaf shows the domains of interest in only a few tools but do not show the original tools themselves in full.

The first three are a replication of how the Victorian data system is set up for workers to enter data into standardised software for PDRSS services (NGOs in Victoria working in psychosocial rehabilitation for persons with mental disorders).

BASIS-32 Electronic data collection tool for use by Victorian (NGOs) ‘PDRSS sector’

Agency name ______________

Outlet Name ______________

Statistical linkage key ______________

Reason for measure ______________

Activity type ________________

Key worker ________________

Date of measure ________________

Status ________________

1. Managing Day to day	12. Recognising emotions	23. Hearing voices
2. Household work	13. Independence	24. Manic behaviour
3. Work	14. Goals or direction in life	25. Mood swings
4. School 5. Leisure	15. Lack of self confidence 16. Apathy	26. Compulsive behaviour 27. Sexual activity
6. Adjusting to stresses	17. Depression	28. Drinking alcohol
7. Relationships with family	18. Suicidal feelings	29. Taking illegal drugs
8. Getting along	19. Physical symptoms	30. controlling temper
9. Isolation or loneliness	20. Fear , anxiety	31. Impulsive behaviour
10. Being able to feel close]	21. Confusion	32. Feeling satisfaction
11. Being realistic	22. Disturbing thoughts	

CAN-SAS (Camberwell Assessment of Need Short Form) Electronic data collection tool for use by Victorian (NGOs) ‘PDRSS

Agency name ______________

Outlet Name _______________

Statistical linkage key ______________

Reason for measure ______________

Activity type ________________

Key worker ________________

Date of measure ________________

Status ________________

1. Accommodation	12. Alcohol
2. Food 3. Looking after home	13. Drugs 14. Company
4. Self care	15. Intimate relationships
5. Daytime activities	16. Sexual expression
6. Physical health	17. Child care
7. Psychotic symptoms	18. Basic education
8. Information on condition	19. Telephone
9. Psychological condition	20. Transport
10. Safety to self	21. Money
11. Safety to others	22. Benefits

WHOQOL – Australian version Electronic data collection tool for use by Victorian (NGOs)

Agency name __________ Activity type __________________

Outlet Name __________ Key worker __________________

Statistical linkage key __________ Date of measure __________________

Reason for measure __________ Status __________________

1. Quality of Life	14. Opportunities for leisure
2. Health satisfaction	15. Physical mobility
3. Physical pain	16. Sleep satisfaction
4.Medical treatment 5. Enjoyment of life	17. Daily living abilities 18. Work capacity
6. Meaningfulness of life	19. Satisfaction with self
7.Ability to concentrate	20. Personal relationships
8. Feelings of safety	21. Sex life
9. Physical environment	22. Support from friends
10. Energy levels	23. Living place conditions
11. Acceptance of body	24. Access to health services
12. Money for needs	25. Transport satisfaction
13. Information availability	26. Frequency of negative feelings