

# Using outcome measures in Mind Australia

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# Acronyms and terms used in this report

AMHOCN	Australian Mental Health Outcomes and Classification Network
BASIS-32	Behaviour and Symptom Identification Scale – 32 items
CANSAS	Camberwell Assessment of Need Short Appraisal Schedule
CANSAS-P	Consumer rated short version of CANSAS
CM	Community Managed also known as Psychiatric Disability Rehabilitation and Support Service
СМІ	Client Management Interface
CRM	Collaborative Recovery Model
HoNOS	Health of Nation Outcome Scale
LSP-16	Life Skills Profile – shortened version
MINDLINK	Mind's Electronic client information data base
NOCC	National Outcome and Casemix Collection
PDRSS	Psychiatric Disability Rehabilitation and Support Service (Victorian state government term used to describe community based, community mental health support services)
CBMHSS	Community based mental health support services (also commonly known as non- government organisations)
NGOs	Non-government organisations
OMs	Outcome Measures
REE	Recovery Environment Enhancing Measure
TheMHS	The Mental Health Services Conference
WHOQoL	World Health Organisation Quality of Life scale
Validity	whether a questionnaire or test measures what it intends to measure. Face validity is a type of validity that is based on whether a measure 'looks like' it is valid, rather than using statistical measures.
Reliability	whether a measure or test has consistency. That is, does the measure produce consistent results under consistent conditions.

# Introduction

The purpose of this discussion paper is to explore key issues in outcome measurement for the community based mental health services sector in general and for Mind Australia in particular. It seeks to advance Mind's commitment to examining the quality and outcomes of its services and will contribute to shaping the discussions and directions about outcome measurement within Mind and other community based mental health support services (CBMHSS) in the context of Mind's ongoing focus on supporting recovery and wellbeing.

This discussion paper is structured to:

- 1. address the context of outcome measurement in this sector
- 2. introduce and review the various types of outcome measures and the issues surrounding their use in Mind and other parts of the CBMHSS
- 3. identify the issues and challenges in relation to moving forward on outcome measurement in recovery oriented services.

Outcome measures have the potential to assist in the assessment of the strengths and needs of consumers and track whether those needs are being met over time. Being able to consistently monitor and report on outcomes for consumers has important implications for supervision of direct service work and monitoring team performance in relation to client outcomes. This enables a culture of service improvement that is focused on gaining the best outcomes for consumers. Outcome measurement in CBMHSS inevitably needs to relate to the overall goals of work in the sector, in particular, its recovery orientation and emphasis on social inclusion and wellbeing.

The measurement of outcomes is recognised as an important component of health and welfare services; however, the nature of recovery oriented practice creates particular problems for the measurement of such outcomes. Outcome measures may be differentiated between subjective and objective measures. Subjective measures are those particularly suited to consumer rated tracking of personal goals and recovery orientation of the service measures and objective measures attempt to monitor change over time.

Recovery based service provision is not an intervention that can readily be subject to clinical trials. It is an approach to mental health that 'represents the convergence of a number of new ideas (empowerment, self-management, disability rights, social inclusion and rehabilitation) under a single heading that signals a new direction for mental health services' (South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust, 2010, p.8). In addition, the literature on recovery emphasises that a recovery approach involves a focus on *how* things are done as well as *what* is done. These different elements create a particular set of technical challenges for the measurement of outcomes for recovery oriented services. These technical challenges will be examined in this paper.

This paper considers the directions for Mind Australia, in regard to outcome measurement for recovery oriented services. It reviews the literature on the utility and adequacy of the existing outcome measurement tools that are in use in Australia. It then offers an analysis and discussion of the strengths and limitations of the current outcome measure technologies in Australia and proposes some directions for Mind and the mental health sector on outcome measurement.

Within Mind and the CBMHSS, considerable effort has been invested in the use of recovery measurement tools. Substantial data has been collected. However, there is a divergence of views about the reliability of this data. There is a lack of consensus about the preferred tools to be used and a lack of consistency of approach. As will be identified in this paper, agencies have been

encouraged to use a range of tools and there has been little focus on cross-agency or sector collection of consistent outcome measures. This lack of consistency creates particular problems for consumers, families and carers, service providers and government in being able to measure and compare outcomes and quality on some reliable basis. This paper argues for the need to move towards a more consistent approach which recognises some of the technical challenges in this sector.

A consistent approach to outcome measures enables and encourages local research activity including improved opportunities to access, use and interpret data. Obtaining informative data about outcomes provides opportunities to reflect on whether services are meeting expectations in relation to both outcomes for clients and also whether services are recovery oriented in practice. Findings can help identify achievements and can also assist in making changes that will enable service improvement. Having a consistent approach to outcome measurement makes sense in being able to gather, compare and contrast findings from relatively large amounts of data; however this requires caution as there is the potential for consistency to mask opportunities for innovation. The sector has the opportunity to undertake further development and encourage innovation in both developing outcome measures and in the systems required to collect and interpret that data—such that it contributes to a thriving research and evaluation culture (Larsen 2008). There are choices to be made in relation to what are the best options for services overall and what requires more finessing at a local level. This is particularly important as services grow and develop and increasingly offer a diverse range of services to a diverse group of consumers and family/carers. This paper argues that the preferred option would be to choose to establish a basic set of outcome measures whilst also including specialised additional measures for specific services or consumers with particular needs. Its findings suggest the need for a more consistent approach and the need for the collection, analysis and publication of outcome data. Outcome measures need to be meaningful, relevant and embedded in data collection systems and broader evaluation plans and should support whole-of-sector analysis.

# The Current Context

The following sections describe the current context of outcome measurement in four areas:

- 1. Mind Australia.
- 2. Community based mental health support services (CBMHSS).
- 3. Commonwealth developments in outcome measures.
- 4. State government directions for the community managed mental health sector.

## Mind Australia

Mind Australia has a commitment to examining the quality and effectiveness of its services, and outcome measurement provides an important contribution to this commitment. Mind has had a history of regularly using the WHOQoL (Appendix 4) and the CANSAS (Appendix 5). As well as these individual outcome measures, Mind has also been engaged in trials of the Recovery Enhancing Environment Measure (REE), involving Mind consumers as consumer researchers in this project. Mind has also been actively engaged in developing measures of consumer satisfaction with service delivery, particularly in South Australia.

Mind's Research and Evaluation Framework (Mind Australia 2011) identifies monitoring outcomes as one of its key platforms. The intention of the outcomes platform is to inform Mind about the outcomes clients achieve and contribute to assessing the contribution Mind's efforts have on these outcomes. However, the general evaluation question of whether consumers and family/carers are

directly benefiting from Mind's interventions will not be answered solely through the use of outcome measures. It is anticipated that outcome measurement will contribute to research, enabling the collection of valuable data that can assist in answering strategic research questions that are important to building the evidence base for Mind's policy and practice.

It is expected that this discussion paper will lead to Mind reconfirming its commitment to outcome measurement and the development of clear and consistent future expectations. Decisions on outcome measures will also inform the further development of Mindlink: Mind's electronic client information database.

## The Community Based Mental Health Support Sector

The National Mental Health Reform 2011<sup>1</sup> has stated that there is significant opportunity to increase accountability and transparency in the current mental health system to better link the investments made by governments to measurable improvements in outcomes for people with a mental illness. The road map encourages a stronger emphasis on partnerships and mental health services breaking down the divisions often created by funding sources. The plan encourages working together to improve access and ensure a stronger focus on the needs of consumers rather than bureaucratically driven service delivery. The plan implies the need to for all specialist mental health service providers to work together to monitor and achieve positive outcomes, particularly in relation to social inclusion and wellbeing.

The national peak body for community mental health and recovery services across Australia, Community Mental Health Australia (CMHA), have been asked by the Commonwealth Department of Health and Ageing to consult community managed mental health services across Australia and their stakeholders about their usage of outcome measurement (OM) tools in service delivery. The CMHA aims to end consultations by June 2013 and aims to advise the commonwealth government on the potential for further development of routine OM in the CBMHSS.

Vicserv, the peak body for the CBMHSS in Victoria recently recommended that the community managed sector continue to use its own knowledge and expertise and work collaboratively with others in Victoria and nationally on outcome measurement. Vicserv identified three high-level outcomes:

- 1. Mental health status addressed. There is no purpose in sustaining a CBMHS service system if it does not make substantial contributions to the mental health of its consumers. This is important even in a context where consumers are acknowledged to have responsibility for their own recovery journey and it is acknowledged that they will face periodic setbacks.
- 2. Recovery support provided. This outcome relates to the need to demonstrate that the services/interventions provided make a tangible difference in the lives of clients, families and carers.
- 3. Capacity to live well in the community. This outcome group relates to the effect that CBMHSS has on acceptance and inclusion. Leadership of the work on outcome measures is already happening in the CBMHSS arena. (Vicserv 2012).

<sup>&</sup>lt;sup>1</sup> <u>http://www.health.gov.au/internet/publications/publishing.nsf/Content/nmhr11-12~nmhr11-12-newapproach</u> (accessed 5th September 2012)

The Mind *Research and Evaluation Framework* (2011) proposed a set of principles that should guide its work in relation to measuring outcomes. These principles, based on those developed by Rethink Mental Illness in the UK, are outlined as follows:

- Outcome measures are consistent with Mind's model of recovery oriented practice.
- Outcome measures are embedded into day-to-day practice (including data collection and storage).
- Outcome measures encourage dialogue and support recovery.
- Outcome measures are appropriate to the needs and circumstances of particular services.
- Outcome measures are done *with* people using services not *to* them.
- Outcome measures used in Mind are well tested and recognised for validity and policy impact.

There is currently significant potential to undertake initiatives that enable a more considered focus on outcome measures currently in use in the CBMHSS and also to trial new outcome measures, particularly those with a recovery focus. As implied above, this activity needs to consider not only *what* is being measured but *how* this is done and whether the purpose and process is consistent with the overall role and purpose of the sector. It also suggests the importance of collaboration with other mental health service providers.

# Commonwealth Government developments in outcome measures: National Outcome and Casemix Collection (NOCC)

The National Outcome and Case mix Collection (NOCC) was introduced in clinical services during 2003–4 and arose from work done for the *Second National Mental Health Plan* to develop infrastructure and skills that would enable quality improvement across the clinical sector (http://amhocn.org/).

Adult clinical mental health service providers have been expected to administer routine outcome measurement with consumers. These clinician administered measures are the HoNOS (a 12 item scale measuring behaviour, impairment, symptoms and social functioning developed in the UK) and Life Skills Profile (Australian scale designed to measure the level of functioning of people with schizophrenia). Consumers are also asked to complete a self-report measure (in Victoria this is the Behaviour and Symptom Identification Scale – 32 items (BASIS-32), in South Australia the K-10+ Consumer self-assessment). State-based resources that explain these expectations are available at the following locations for Victoria, South Australia and Tasmania:

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

http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/health+s ervices/mental+health/national+outcomes+and+casemix+collection

http://www.dhhs.tas.gov.au/ data/assets/pdf\_file/0007/38509/Assertive\_Case\_Management Resource\_Manual\_version\_1\_.pdf

The Commonwealth is also undertaking a new initiative to develop the Living in the Community Questionnaire (previously referred to as the Social Inclusion Scale). The Training and Service Development component of the Australian Mental Health Outcomes and Classification Network (AMHOCN TSD) has been funded by the Australian Government's Department of Health and Ageing to develop a measure that focuses on social inclusion as an important indicator of recovery. A Technical Advisory Group has been involved in the development of the measure. At The Mental

Health Services conference (TheMHS) in both 2011 and 2012, Tim Coombs presented the results of the consultations and brief pilots of the tool. The results of this work indicated the need for further development. The measure is being developed to report on five indicators of the reform agenda outlined in the *Fourth National Mental Health Plan*. The domains in the scale have generally been supported (social activities, employment, housing stability, education, physical health, social support and control) but further work needs to occur in relation to the phrasing of the questions and its design (T. Coombs, personal communication). How this tool is to be used is yet to be determined but development is progressing. The scale represents an outcome measure because it is able to track the amount of time the person completing the tool spent engaged in social inclusion activities as represented by the domains in the scale. While the measure is still in the developmental phase updates on the development process are available via the AMHOCN website (Australian Mental Health Outcomes and Classification Network. 2012). <u>http://amhocn.org/special-projects#a 647</u>

The current plan, according to TheMHS 2012 is to 'go back, redesign and come out with a shorter more consistent tool that measures both objective and subjective domains of social inclusion' (TheMHS blog: <u>http://mentalhealthconnect.com.au/wordpress/</u> accessed 23/08/2012).

## State Government directions

It has been suggested that routine outcome measures have been underemphasised in the community based mental health support sector despite the considerable efforts to collect outcome data in the clinical side of service delivery (Tobias 2010; Australian Mental Health Outcomes and Classification Network 2012).

In 2004 the Victorian Department of Human Services policy in relation to outcome measures in the Psychiatric Disability Rehabilitation Support Services (PDRSS) (or CBMHSS) explained that, in contrast to the clinical sector, there are three self-assessment measures in use in the sector but no universal complementary service provider-rated measures. The policy identifies and approves the use of separate outcome measures in use in community managed mental health services in Victoria: the World Health Organisation Quality of Life scale (WHOQoL), the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) and the BASIS-32. The emphasis is placed on offering service users an opportunity to rate their own mental health and encourages services to collect consumer ratings and to analyse them locally. The policy anticipates that only programs who do individual program planning would find these measures relevant. Therefore self-help, drop-in or respite services are not required to do outcome measurement.

In the case of the Victorian Government, monitoring the sector's performance has largely been through a requirement to report to government about inputs and activities, not outcomes for clients. This is similar to South Australia where, although the CANSAS is a requirement in the Individual Psychosocial Rehabilitation Support Service (IPRSS) and Returning Home programs, it has had limited use as an outcome measurement tool. This lack of accountability for outcomes reported back to government may be contributing to inconsistency and a relative lack of emphasis on the value of outcome measurement in the sector (Tobias 2010).

There are a number of explanations about why there are not more obligations on the community based mental health support sector in comparison to clinical or public mental health services. First, there is the issue of some types of services not seeming to be suited to outcome measurement as it is commonly used – that is at the beginning and end of an 'episode of care', therefore, as described above, some services are not suited to this type of tracking of outcomes. Another issue is the diversity of outcome measures used within and across different states that appear to vary in focus and measure different things. This may have created confusion about what CBMHSS should be monitoring. Finally, the expectation of local system development rather than a more top down

approach appear to be contributing to variations in commitment to outcome measures in the CBMHSS.

In Victoria, the government recently developed a consultation paper: The Psychiatric Disability Rehabilitation and Support Services Reform Framework (Victorian Department of Health 2012). The paper places significant emphasis on the need for CBMHSS to improve their ability to provide evidence that they are achieving recovery and social inclusion outcomes, in particular in relation to physical and emotional health, social participation, education and employment.

The consultation paper makes the following specific reference to outcome measurement:

Outcome measurement is an important way to determine the impact that services achieve on client outcomes over time. The collection of routine outcome measurement is required for all clients of specialist clinical mental health services. The Victorian Government encourages PDRSS to use the same outcome measurement tools as the specialist clinical mental health services, but this is not a requirement. Agencies currently use a range of outcome measurement tools. The variety of outcome measurement tools utilised, however, does not enable reliable comparison of achievements of client outcomes from provider to provider. PDRSS use of the same outcome measurement tools as the specialist clinical AMHS could enable more effective analysis of an individual's progress across the specialist mental health system. (p.35)

The consultation paper emphasises a focus on outcomes related to client identified recovery goals while it also recommends the use of the tools used by the clinical sector. This is a potentially contradictory expectation while the outcome measurement tools in the clinical sector remain focused on symptoms and functioning. Although the possible introduction of a recovery outcome measure has been considered (Pirkis, Burgess et al. 2005), the clinical sector does not as yet have a recovery focused outcome measure in the current suite of outcome measures. The outcomes mentioned here do have significant correlation with the development of the Living in the Community Questionnaire and confirm its potential relevance to the sector.

# **Measuring outcomes**

This section provides an overview of some of the important conceptual issues related to outcome measurement within the community managed sector. The literature explains that outcomes can be collected and analysed in different ways depending on the questions they are informing. For example, in relation to recovery measures, Burgess et al, 2010 have identified the difference between personal recovery measures and recovery orientation of the service measures. The type of measure may lead to noticeable differences in when and how these measures are used.

The Planigale literature review, *Reconciling Measurement of Client Outcomes in Homelessness Services,* provides a useful discussion about some of the complexities of measuring outcomes and how to use this data once it is collected (Planigale 2011). It supports the potential for interfacing with other data bases, for example, in the CBMHSS this would most likely be with clinical outcome measurement data. This can occur through the use of unique identifiers. Interfacing could increase the scope and usefulness of the analysis and provide simple but useful information. For example, in relation to rates of re-admission to hospital and other episodes of care, changes to employment or housing status, physical health information and other recovery or social inclusion indicators. This could enable simple percentage-based analysis, for example monitoring the percentage of consumers to achieve a particular outcome in a period of time. Having consistent outcome measures across the different databases may also assist in monitoring progress in the longer term.

A wide variety of other factors, beside the type and quality of services, influence consumer outcomes and this needs to be included in outcomes analysis. Expectations need to be adjusted depending on a good understanding of the differing complexity and severity of presenting need so that fair comparisons can be made about what outcome measures are indicating about different groups of consumers (Planigale 2011). It also assists to compare outcomes across sub-groups to help identify differing effectiveness for particular groups and/or for those with particular needs or goals or patterns of service usage. This is discussed by Trauer (2010,a) who distinguishes between people who are likely to achieve benefit from an intervention, therefore suggesting the need for before and after assessments, and those who might be better considered in relation to 'with or without' in contexts where the main focus may be general support and preventing deterioration. Another way of thinking about outcome measures is whether it's about people 'returning to normal'. This is particularly relevant to situations where people have a transient mental health challenge, and this may be more relevant when working with people in crisis or acute services (Trauer, 2011).

Triangulation of quantitative outcomes data with information from other sources about processes, resources and the broader context enhances the credibility of findings and builds a deeper understanding of what outcomes are being achieved and why (Planigale, 2011). Many clients are more interested in assessing the effectiveness of services based on process issues, such as whether they were treated with respect, rather than what was achieved at the end of an episode of care. Hence the relevance of having a set of principles that guide how outcome measures are implemented and conducted in the organisation.

# Implementing Outcome Measurement in the Community Based Mental Health Support Sector

## Rationale

There is always the possibility that the purpose of measuring consumer outcomes could be challenged when this potentially adds to administrative burden and may not result in service improvement. It might be seen as gathering data to satisfy external expectations rather than having everyday meaning regarding quality and knowledge generation. In order to ensure the latter a number of issues need to be considered, including; how reports about outcome measures are generated; how often and how clear the information generated is; and how meaningful and accessible the data is to consumers and family/carers as well as staff, management and funders. Therefore, making a commitment to consistent outcome measurement requires a 'whole of organisation' response that positively embraces the opportunities inherent in gathering consistent, purposeful outcome information.

## Finding the tools that work for the sector

The main tools used by the community based mental health support services each have advantages and disadvantages. There are considerable developments in the use, and experience with, outcome measures across the sector and the following section of this paper does not seek to try to completely catalogue that diversity of experience. However, the tools discussed below are those that have become familiar in the sector and therefore, in consultations undertaken by the authors, issues could readily be identified in their use (See Appendix 1 for further comparison of the measures).

#### The WHOQoL:

The WHOQoL-BREF (see Appendix 4) is a self-administered 26 item questionnaire, which measures quality of life in four separate but related domains: 1) Physical health, 2) Psychological health, 3) Social relationships and 4) the Environment. It also provides for an overall assessment of quality of life and health as perceived by the client. In Victoria the WHOQoL has been a commonly used outcome measure. It has also been used by Mind services in SA and it is recommended that Tasmanian Community Service Organisations use WHOQoL, however this recommendation needs to be supported through further training of staff. It is important to note these different preferences across states as they become important in the context of many CBMHSS, such as Mind, operating across more than one state.

Various efforts have been undertaken to use the WHOQoL as a service evaluation tool (Mind Australia 2011). This has resulted in presentation of findings, recommendations and considerable support for the ongoing use of the WHOQoL because it could be used as:

- a client tool to support the development of individual recovery plans or IPPs
- a program evaluation tool
- an overall data gathering tool for Mind (or RFV as it was at that time).

A summary of an internal report on the use of the WHOQoL in Mind by Trauer (2006) stated as follows:

Significant problems were encountered in the extraction of the data from the spreadsheet files...The available assessments had very few items omitted, suggesting that the measure was acceptable to those who completed it (we don't know about those who didn't complete it). Examination of the correlations between the items suggested that the scale works as a global measure of quality of life at least as well as a measure of the four domains. Clients'

scores in all four domains were well below those of a community sample. There was a general increase in scores according to month of assessment, with the greatest increase being between the first and second assessments. Using an approach that calculated the slope of score against time, we found most slopes were quite small, indicating small changes over time. Nevertheless, there was a small preponderance of clients with positive slopes (55%) over those with negative (41%) or zero slopes (4%). In terms of change on the four WHOQoL domains, the greatest gains were made in the Social and Psychological domains (5.3 and 4 points respectively between earliest and latest assessments), and the smallest in the Physical (2.4 points) and Environmental domains (-.5 points).

In a later internal report of an analysis of WHOQoL responses collected from 104 SA clients (Agni, 2008) it was indicated that in general, clients experience improved quality of life whilst participating in a Mind program. Again it was found that, on average, clients report a much lower quality of life on entry into Mind than the average Australian population norms. However, in this example, this discrepancy is gradually reduced over time with clients showing incremental improvement in each of the four Quality of Life domains. With the exception of the Social Relationships domain, the gains made in the Physical, Psychological and Environment domains increased or maintained over an extended period of time. The improvement in the individual domains tended to have a cumulative effect resulting in a substantial increase in overall quality of life.

In summary, the advantages of the WHOQoL as identified via consultations with current Mind staff and others are:

#### WHOQoL Advantages

It is consumer rated, reasonably short and most consumers have been able to undertake the measure without assistance or interpretation.

It is a broad, commonly used measure so comparison with general community samples can be undertaken.

The WHOQoL measures self-perceived quality of life which appears to be compatible with recovery concepts.

There is evidence that measuring quality of life relates well to whether consumers' needs are being met – that is – as needs are met – quality of life improves (Slade, Leese et al. 2005).

#### **WHOQoL Disadvantages**

There have been difficulties in being able to obtain a lot of useful and positive data on the whole from this measure. This may be because a consumer's perceived quality of life may not directly correlate with engagement with and progress through services as described above. This may also relate to problems identified with quality of life as an outcome measure because of common discrepancies between service provider and consumer judgements about quality of life (Trauer, 2010, b).

It is not included in the clinical outcome measures suite.

It is not specifically a recovery measure.

It is not used consistently despite efforts to embed its use – suggesting that a number of issues need to be addressed, including how meaningful the data has proved to be, whether it is suited to a diverse range of services, the need for consistent and regular training to use the measure and the lack of integration of WHOQoL data into service planning and delivery.

#### The CANSAS and CANSAS-P

The CANSAS (see Appendix 5) can be relied on to assess met needs and unmet needs and then changes to these needs over time and therefore has potential as an outcome measure. The use of the CANSAS as an assessment tool is a requirement of the Individual Psychosocial Rehabilitation and Support Services (IPRSS) and Returning Home programs in South Australia (SA). The IPRSS and Returning Home programs in SA have been funded since 2005 and operational protocols developed required the use of the CANSAS with consumers in order to inform and develop the Individual Service Plan (ISP). In these contexts the CANSAS use has been primarily encouraged as an assessment tool and not an evaluation tool. In 2006 training was funded by SA Health for NGO staff in the use of the tool. It was recommended that the tool be used six monthly as part of the ISP review process and analysed in conjunction with WHOQoL data. In 2009 IPRSS Operational Protocols state that the use of the CANSAS is required at the commencement of service but do not give recommendation for frequency of use. There have never been any reporting requirements in relation to use of the tool. Mind, like other CBMHSS, has required staff in these programs to complete the tool every six months with consumers. Notably services are generally not expected to report on the results of the tool. At Mind, staff have continued to require training in the use of the tool in order for it to be meaningful. There is no recent history of any data analysis having been undertaken on CANSAS data within Mind. Other Victorian community managed services have also been using the CANSAS as an assessment and evaluation tool and Tom Trauer (personal communication) is confident that CANSAS can provide outcome data, at the very least, CANSAS is effective in detecting changes in need (Trauer, 2010, b). In summary, the advantages of the CANSAS are:

#### **CANSAS Advantages**

The CANSAS has been identified as being a useful tool to assist in developing care plans or recovery plans with consumers and it is recommended to use the CANSAS as a tool to undertake reviews every six months.

The CANSAS may be both consumer and worker rated and this can be a useful way of comparing worker and consumer perspectives. Comparing consumer and worker ratings can promote useful discussion around perceived differences in areas of need. It may therefore shape service delivery and assist in monitoring of recovery goals.

The CANSAS data can be used to compare levels of unmet needs over time.

Where it might be considered as an outcome measure is in its capacity to be useful in assisting to monitor progress and changes in needs over time.

#### **CANSAS Disadvantages**

Because it is not reported on externally and because it may only be useful in contexts where care plans or recovery plans are embedded into service delivery, administration of the tool is variable

across workers, programs and teams.

Anecdotal feedback from Mind staff is that, as a tool, the CANSAS has been subject to criticism as not user-friendly. Consumers generally cannot use the tool unassisted. The actual written explanation of life domains or areas is not straightforward and usually requires the worker to provide an explanation. Therefore use of the CANSAS requires ongoing training and support.

The CANSAS-P is a consumer rated short-form of CANSAS that is compatible with personal recovery. The CANSAS-P has received significant support in the literature as consumer rated short version of the CANSAS (Trauer, Tobias et al. 2008; Van der Krieke, Sytema et al. 2011).

#### **CANSAS-P Advantages**

The CANSAS-P is more user-friendly than CANSAS.

#### CANSAS-P Disadvantages

As with CANSAS-P it may only be useful in contexts where care plans or recovery plans are embedded into service delivery and, as an outcome measure, is limited to indicating changes in unmet need.

#### The BASIS-32.

As discussed above, the BASIS-32 is a consumer rated outcome measure included in the Commonwealth NOCC suite of outcome measures. It is actively used by clinical partners in Victoria. It has not been used as an outcome measure in Mind but is included in the group of measures initially recommended by the Victorian government for the sector and therefore likely to be currently in use in some CBMHSS.

#### BASIS-32 Advantages

It is included in the clinical outcome measures suite and is consumer rated; therefore, it could facilitate interface between outcome measures collected by clinical services and the CMMHS.

#### **BASIS-32 Disadvantages**

It is lengthy and has a significant focus on symptoms of mental illness rather than emphasising recovery goals.

There is minimal evidence of use of the BASIS-32 currently or in the past at Mind although it is likely to feature in the work of our clinical partners and other CBMHSS.

Although the BASIS-32 should be part of routine outcome measurement in clinical practice, completion rates are generally well below expectations (Pirkis and Callaly, 2010).

Use of the BASIS-32 attracts a fee in States other than those that have a licence – such as Victoria. Therefore may not be suited to an organisation that works across multiple states.

## **Recovery measures**

Burgess et al (2010) investigated the suitability of a recovery outcome measure for use across all specialist mental health services. What they found was a diversity of measures that were inconsistent in approach and not necessarily compatible with the Australian context.

They made a distinction between the measurement of individual recovery and the recovery orientation of the service and emphasised the importance of distinguishing between these two different types of recovery measures. The Mind *Research and Evaluation Framework* makes this distinction and also indicates that there are differences between measures focused on assisting to identify change that has resulted from intervention and those focused on assisting consumers to identify their goals and track their personal recovery journey. The criteria developed by Burgess et al (2010) have been adapted to compare individual and service outcomes measures in the community managed sector for consideration in Appendix 1.

Wilson, Jenkin and Campain (2011) make a distinction between outcomes for individuals, outcomes for communities and outcomes at the level of services. Although it may be a future consideration, this discussion paper will not address the issues related to communities although, as the CBMHSS grows and develops, this may be an option for the future.

## Individual Recovery Instruments

Outcome measurement can be divided into three dimensions – the person dimension, the change dimension and the service dimension (Larsen, 2008). The first two dimensions relate to the single question of whether the service is contributing to the individual recovery journey of clients. It suggests that this needs to be measured in two different ways: 1. through ensuring that clients are able to identify recovery goals and track their own progress and; 2. the other is to more objectively measure whether change occurs in relation to recovery, social inclusion and wellbeing for our clients over time.

Individual recovery measures were considered by Burgess et al (2010) and their research yielded 33 instruments, of which 22 were designed to measure an individual's recovery and 11 were designed to assess the recovery orientation of the service (or providers). They applied a hierarchical set of criteria to assess the instruments and reduced the pool to the following four candidate instruments designed to measure an individual's recovery:

- 1. Recovery Assessment Scale
- 2. Illness Management and Recovery (IMR) scales
- 3. Stages of Recovery Instrument (STORI)
- 4. Recovery Process Inventory

Although they got down to this short list of four, the review was not able to identify a preferred instrument; each had strengths and weaknesses and none was considered currently suitable as a recovery measure for clinical services without modification being required. The review also did not identify any instruments that had established sensitivity to change. It seems that a key challenge for the future and further development of personal recovery outcome measures is the question of sensitivity to change (Pirkis, Burgess et al. 2005). It may be more appropriate that when it comes to the change dimension, other outcome measures that have been identified as sensitive to change need to be relied on.

Even so, as discussed by Trauer (2010,a), it has been suggested that recovery is such a personal journey that it can't be measured—that it is futile to apply objective measures to subjective

experiences. The alternative is to measure the individual experience over time to achieve a pre and post measure of individual change processes. There have been many attempts to try to capture what outcomes consumers are experiencing in recovery oriented services. As indicated above, in the community based mental health support sector, it would appear that one of the best ways to track personal recovery outcomes is via Individual Service Plans or Recovery Plans. This enables a focus on consumer developed goals and self-directed tracking of progress in relation to these recovery goals. Although this may work well in the context of service delivery, one of the problems here is that it is difficult to turn this into 'data' that can be used to establish evidence about recovery outcomes. One attempt to address this problem has been the development of the Recovery Star in the UK (Dickens, Weleminsky et al. 2012; Triangle Consulting and Mental Health Providers Forum. 2012).

#### **The Recovery Star**

A description of the Recovery Star and the process of its development is available on the website as follows:

In 2008 Mental Health Providers Forum (MHPF), with Triangle Consulting, worked with service users and several of our members to develop what is now the Mental Health Recovery Star—a key-working and outcomes measurement tool.

The Recovery Star tool, which was recommended by the Department of Health New Horizons programme (2009), has been developed for use in adult services. As a key-working tool it enables staff to support individuals they work with to understand their recovery and plot their progress. As an outcomes tool it enables organisations to measure and assess the effectiveness of the services they deliver (Mental Health Providers Forum. 2012).

Core dimensions of the Recovery Star: Managing mental health, Physical health & self-care, Living skills, Social networks, Work, Relationships, Addictive behaviour, Responsibilities, Identity & self-esteem, Trust & hope.

A key value of the Recovery Star (and other similar personal recovery goal self-tracking outcome measures) is that it provides a person-centred opportunity to establish and track recovery goals over time. The Recovery Star software can show this visually by animating a time sequence of intervals showing progression outwards and inwards on the various axes of the outcomes star, enabling both assessment of where someone is on their recovery path and consumer-worker discussion about what affects progress and retreat over time.

Burgess et al (2010) did not include the Recovery Star in their review because it had not been scientifically scrutinised. However, Dickens et al (2012) recently examined the psychometric properties of the Recovery Star and reported that it measured an underlying construct relating to recovery (thereby demonstrating internal consistency); and that it showed a two factor structure that was tentatively termed 'internal management and personal relationships' (factor 1) and 'external management and external relationships' (factor 2). Ability to measure change over time was small but this may have been due to a short period between test and retest. The external validity of Recovery Star has been challenged, with the suggestion that any correspondence between the recovery construct measured by Recovery Star and the individual's own priorities for recovery are coincidental (Killaspy, Boardman et al. 2012). Ongoing research continues to assess these issues, but Killaspy et al (2012) again raise the concern about whether it is suitable to apply objective tests to measures of subjective constructs.

## **Recovery Orientation of the Service Measures**

The four candidate instruments identified by Burgess et al (2010) designed to measure the recovery orientation of the services were:

- Recovery Orientated Systems Indicators Measure (ROSI)
- Recovery Self-Assessment (RSA)
- Recovery Orientated Practice Index (ROPI)
- Recovery Promotion Fidelity Scale (RPFS)

Once again Burgess et al (2010) did not recommend any one of these measures as a suitable recovery measure for the public mental health sector. Each had advantages and disadvantages.

Burgess et al (2010) decided to exclude the REE, a recovery orientation of service measure that has previously been trialled in Mind and other CMMHS, because it was determined to be 'not manageable (it has a total of 166 items) and easy to use in terms of administration' (p.24, 2010). Burgess et al (2010) did not consider the Elements of Recovery Facilitating Systems (ERFS) which is a simplified derivation of the REE because it has only recently been developed. The ERFS describes the features of a recovery oriented mental health service and captures the person's view of how well the service they use meets that profile. It is designed for use in service evaluation and to stimulate awareness of service strengths and areas for improvement. It has been selected and trialled in an outcome measures project in Devon in the UK (Recovery and Independent Living Professional Expert Group 2009).

#### The Recovery Environment Enhancing Measure (REE)

Even though Burgess et al (2010) did not see the REE as suitable for clinical services and the accepted problem with it being so long, the REE has received some support in the literature and has been piloted at Mind, with positive consumer feedback about the measure and findings that have proved useful to service development.

Amongst the thirteen measures provided by Campbell-Orde et al (2005), the Recovery Environment Enhancing Measure (REE) (Ridgway 2005) was identified as standing out as one of the few that examines both individual recovery and the service environment that supports recovery. The REE potentially enables researchers to measure both the factors individuals consider important to their recovery, as well as how well the service environment supports them in those areas. This can help services to identify the importance consumers place on factors that promote recovery and resilience, and determine where to direct their time and efforts.

The REE was developed using consumers' accounts of recovery and what environmental factors supported them. It was tested on consumers from the Kansas Consumers as Providers program and was refined based on their feedback, as well as feedback from other people with backgrounds as users of mental health services, such as Patricia Deegan. Therefore it challenges one of the criticisms of outcome measures that they are usually developed without the input of consumers (Trauer, 2010, a). Consumers complete 24 scales, each of which commences with a 'header' question which asks them how important a particular element is to their recovery. It is followed by three questions that ask how well the service environment supports the area of recovery raised in the header question. There is also a section covering five special needs, that only need to be completed if they are relevant to them and, finally, there are questions about organisational climate, recovery markers and a feedback section.

#### The Mind pilot study of the REE

The pilot study was conducted in order to ascertain the suitability of the REE as a measure of recovery outcomes in Mind. Given that the REE asks respondents how well the organisation is supporting their recovery, there was an inherent problem with Mind staff administering the measure. An innovative aspect of this pilot study was the employment of consumer researchers to seek the views of consumers.

There were 40 male and 31 female participants who were consumers of seven Mind programs. Consumers generally found the REE to be a good measure of recovery and were positive about its use as an ongoing measure by the organisation. Given the time people took to write long-handed answers to the open questions at the end of the survey, the REE seemed to inspire considered thought and self-reflection. On the whole, despite a couple of concerns, the REE appeared easy to complete. The recommendation from the pilot study was that the REE is an adequate tool for Mind to measure how well it supports its consumers in the areas of recovery identified as important to them.

The data provided a voice for consumers to tell the organisation directly and specifically about what they feel is being done well, and where more support is needed. However, the REE appears to have many limitations as an outcome measure, in particular because of its lack of established psychometric properties (Ridgway 2005), its length and the emphasis on using consumer researchers in its administration means that it is a very resource intensive measure that therefore may not be regularly repeated.

# **Satisfaction Surveys**

Satisfaction surveys are another way of receiving feedback about how a service is performing. Although a popular method of obtaining feedback, they are contested on methodological grounds and often seen to be skewed towards positive findings. They may also be disputed as unreliable (Luxford, 2012). However, some services have been committed to the development of good quality satisfaction surveys. Rethink Mental Illness in the UK developed a survey that is based on recovery orientation of the service measures. They have produced a subsequent report and set of recommendations and are committed to continuing to use a satisfaction survey (Larsen and Weeks 2011). In 2011, at The Australian Mental Health Services conference (TheMHS), Dr Grenville Rose, from Aftercare in Sydney, reported on a Service User Constructed satisfaction survey. The following provides a summary of this activity:

'In 2007, Aftercare—along with partner organisations New Horizons and the University of New South Wales—received funding from the Mental Health Coordinating Council (MHCC) to undertake an extensive satisfaction survey of consumers across all services. A first wave of data was collected and analysed, and staff training was devised based on the analysis. A second wave of collected data showed that our client satisfaction had increased and that this increase was probably due to the training our staff receive' (Rose 2012).

The Verona Service Satisfaction Scale, developed in Italy, has been used in psychiatric services worldwide to measure the expectations and satisfaction of patients, relatives and professionals with mental health services (Ruggeri 2010). Results of the survey have been used to recommend organisational change and some consistency internationally has been found in relation to the need to pay closer attention to interactions between consumers and some members of staff and also the need to undertake more careful assessment of the social problems that consumers experience.

Recent studies have provided defence of satisfaction surveys (Luxford, 2012). Although the literature often refers to the physical health and hospital domain, key findings have been that high patient

satisfaction scores were sometimes more indicative of quality than routine clinical outcome measures. It also found that patient satisfaction was most often linked with good communication and positive interactions with staff (Boulding, Glickman et al. 2011; Luxford, 2012).

In an expansion of the satisfaction survey concept, the Victorian Mental Health Carers Network, in partnership with the consumer peak body, the Victorian Mental Illness Awareness Council and the Department of Human Services, have undertaken a pilot survey of Consumer and Carer Experiences of Mental Health Services (Victorian Department of Health. 2010). This initiative gathers information from consumers and carers about their experiences of services in clinical mental health and community managed services, and develops mechanisms for enhancing consumer and carer participation in service quality improvement. Known as the MH Eco, this initiative has received national and international interest and is contributing to the development of a nationally consistent survey tool. This tool will move away from asking about satisfaction with services and will focus more on the experience of consumers and families when accessing services. The national tool is currently being trialled to investigate whether it provides good information and is easy to complete (Victorian Department of Health. 2012 (b)). The development of this tool has important implications for Mind as it may be a future expectation that services use a standardised national tool to investigate consumer experiences of mental health services.

Another related development is the Australia's National Mental Health Commission *Contributing Life Project*. The project commenced in October 2013 and will develop a methodology, processes and a framework to qualitatively compile and report on the experiences of Australians with mental health issues and their families and supporters. The Commission intends to regularly collect qualitative information about people's real and whole of life experiences through this initiative. The commission wants to use this data to build a more rounded picture of service and support outcomes through its annual National Report Card on Mental Health and Suicide Prevention.

## Implementing Consumer Satisfaction Surveys

Mind has been undertaking an annual consumer satisfaction survey since 2007 in SA (see Appendix 3). The survey was developed by external consumer consultants, and wherever possible has been administered by consumer consultants. Results obtained have been on the whole highly favourable. Interestingly, information and feedback obtained from consumers has been in line with the Mind Strategic directions; namely, that Mind needs to do more around the social inclusion areas of housing and employment, and there is much room for improvement around community and social involvement.

In late 2011 Mind Prevention and Recovery Care Services (Victorian PARCs) began a three month pilot of a consumer exit survey based on the consumer satisfaction survey developed by Rethink Mental Illness in the UK (see Appendix 2). Prior to the pilot, each PARC service was using its own locally developed exit survey. When questions and content were compared similarities and differences were found but all were within the scope of the Rethink survey. The Rethink survey was attractive because it was subject to considerable consultation with staff and consumers in its development. The findings have provided useful information for service development and improvement.

# **Outcome measures for families and carers**

Obtaining the perspective of families and carers, and improving outcomes for families and carers potentially provides an important component of measuring outcomes and is consistent with the emphasis placed on improving outcomes for families and carers in the *Fourth National Mental Health Plan*. Mind's framework or model of services for families and carers can be described as having three components: 1) family sensitive practice; 2) short term, targeted, services for families

or carers and; 3) specialist family services. Each of these components suggests the need for different outcome measures focused on families and carers. Although interrelated, 1) has an emphasis on obtaining evidence about whether Mind services are sensitive to the needs of families and carers; 2) and 3) are focused more on whether families and carers experience positive outcomes as a result of their contact with Mind. Therefore, Mind faces a future challenge in implementing outcome measures for families and carers in a variety of contexts.

A scoping exercise in relation to carers has been undertaken by the Australian Mental Health Outcomes and Classification Network (Dare, Hardy, Burgess, Coombs, Williamson, Pirkis, 2008). Of the six instruments they short listed, none were seen as an ideal measure of outcomes for carers of people with mental illness. Although there was reserved support for two measures, the CarerQoL-7D+VAS and BAS, problems were identified in relation to terminology, technicality and administration; furthermore, they did not adequately reflect the 'journey' of caring for a person with mental illness (Dare et al, 2008, p.14). Feedback from families and carers suggested that more needed to be done to meet carer needs in services before an outcome measure would be meaningful.

Some outcome measures, such as the Recovery Assessment Scale (RSA) have carer versions (O'Connell, Tondora, Croog, Evans and Davidson, 2005; Burgess, et al, 2010) and this is an opportunity for comparison of perspectives and also, in the case of the RSA at least, for carers to comment on the extent to which recovery-supporting practices are evident in the service they are accessing.

Gaining the perspective of families and carers through outcome measurement tools or carer satisfaction surveys appears to be consistent with the roles and purpose of the CBMHSS. However, attempts to do this, at least as indicated by projects at Mind, have highlighted many of the issues and difficulties that arise in undertaking a thoughtful, practical and ethical approach to surveying the opinions of individual family members or carers who are the relative or carer of a particular consumer. This is also potentially a very resource intensive exercise. There have been attempts to survey families and carers using mental health services including the Mental Health Council's National Carer Survey (http://www.mhca.org.au/). But enabling carers to access a survey, such as this one, requires services to utilise carer information from detailed and up to date data bases to ensure carers were regularly informed about any opportunities to provide feedback. In Mind's experience, recording family and carer information, accessing it and then using this data base requires further policy, procedure and practice developments.

As discussed above, MH Eco is an evidence based methodology that utilises consumer and carer experience to improve mental health services and this method enables collection of information through interviews to identify areas of excellence from family and carer perspectives and opportunities for improvement. This information from families and carers can then be used to consider future action and service improvement. Therefore MHEco represents a good place to start.

# Conclusion

Outcome measures can inform services about the outcomes clients achieve and how the service is contributing to these outcomes. However, the general evaluation question of whether consumers and family/carers are directly benefiting from interventions will not be answered solely through the use of outcome measures. This broader question inevitably invites a number of different but complementary evaluation and research activities. Developing high quality and consistent approaches to assessing outcomes forms one contribution to improved understanding of what appears to be happening over time when consumers access our service and whether this is consistent with what the community based mental health support sector and our consumers expect.

Outcome data can be part of a feedback loop that supports service development initiatives, supporting continuous improvement.

It is recommended that recovery oriented services, focus on three outcome dimensions:

- a. Person dimension: are services enabling consumers to develop and monitor their own recovery goals?
- b. Change dimension: are we able to measure or assess any change the person experiences as a result of using the service/s over time?
- c. Service dimension: are we able to measure or assess whether, or to what extent, the aims of the service are being achieved, or address the question 'are we recovery orientated and to what extent? '(Larsen, 2008)

Therefore outcome measurement includes both subjective and objective measures that enable the tracking of personal goals, measure changes for clients over time and ensure the service is recovery oriented. The community managed mental health sector in Australia is currently engaged with outcome measurement and has a history of using and favouring various tools. However, the future requires a more considered and consistent approach to outcome measurement that is clearly focused on recovery, social inclusion and wellbeing. Increasingly large and complex organisations that operate across multiple states in Australia, such as Mind, have an opportunity to provide leadership within the sector and to use outcome measurement to support the development of a strong evidence base for recovery focused service delivery. The challenges lie in the choice and use of appropriate tools, and in ensuring consumers, family/carers and staff are engaged in embedding outcome measures into day to day practice. Furthermore, effective use of outcome measures requires training and support, clear and regular reporting and useful, well analysed data that enables ongoing service planning and improvement.

The purpose of this discussion paper has been to place the further development of outcome measurement in the community managed sector in the context of current policy and practice, enabling learning from history and identifying future challenges. The following questions need to be considered:

- Are the three dimensions of outcome measurement proposed in this document meaningful?
- What outcome measures are going to work best for the community managed mental health services?
- What support is required to enable the most consistent and effective use of outcome measures? For example, engaging consumers and family/carers in planning and implementation, staff supervision, IT support and quality activities.

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		<b>Possible Criteria</b>	for Rating INDI	/IDUAL Outcome	Mea	sures *			
Outcome Measure	Explicitly measures domains related to personal recovery **	Is brief and easy to use (≤50 items)	Takes a consumer perspective	Yields quantitative data	a) b)	Has been scientifically scrutinised; Demonstrates psychometric properties	Applicable to Australian context	Acceptable to consumers	Issues for community managed mental health services
BASIS-32 Behaviour and Symptom Identification Scale – 32 items	Questionable – 2 items address hope indirectly. Items on abilities, autonomy, social, positive sense of self are included, but no items on meaning/purpose in life.	Yes, 32 items	Yes. Self- rated	Yes		a) Yes b) Yes	Yes	Yes	Identified as being too clinical in its orientation – many items assess clinical functioning or symptoms, eg. items 16-31.
CANSAS Camberwell Assessment of Need	No items on hope, abilities, meaning/purpose in life, positive sense of self. Active engagement, autonomy and social issues indirectly addressed.	No, although it only has 22 items, assistance is usually required	Yes	Yes		a) Yes b) Yes	Yes	Yes- although Mind staff report that it is not user- friendly.	Can compare worker and consumer ratings to generate discussion on differences.
CANSAS-P Camberwell Assessment of Need Short Appraisal Scale	As for CANSAS	Yes, 22 items	Yes, self-rated	Yes		a) Yes b) Yes	Yes	Yes - The CANSAS-P is designed to be more user-friendly than CANSAS and does not involve staff as an 'intermediary' (Trauer et al, 2008)	The CANSAS-P has received significant support in the literature as a consumer rated version of the CANSAS

# **Appendix 1: Criteria for Rating Outcome Measures**

\*Adapted from Burgess et al (2008). These criteria were developed by Burgess et al for clinical settings. The final column has been added to consider issues in community managed mental health service settings.

\*\* These recovery domains come from Victorian Government Recovery Framework Report and are; gaining and retaining hope; understanding one's abilities and disabilities; engagement in an active life; personal autonomy; social identity; meaning and purpose in life; positive sense of self.

		Possible Criteria for Ra	ting INDIVIDUA	L Outcome Meas	sures	*			
Outcome Measure	Explicitly measures domains related to personal recovery	Is brief and easy to use (≤50 items)	Takes a consumer perspective	Yields quantitative data	c) d)	Has been scientifically scrutinised; Demonstrates psychometric properties	Applicable to Australian context	Acceptable to consumers	Issues for PDRS
WHOQoL- BREF	May measure hope through spirituality domain; abilities and autonomy may be measured through independence & environment; social identity and active engagement may be in social relationships; positive sense of self in psychological domain.	26 items – rated by Mind staff as reasonably short	Yes	Yes		a) Yes b) Yes	Yes	Yes	Data has been identified in consultation as not useful perhaps because consumer's perceived QoL may not directly correlate with Mind service engagement.
Recovery Star	Some domains are contested (eg. Abilities; Meaning/purpose).	10 domains that require assessment across a 10 point scale. While it is not brief, this may not be a problem for PDRS.	Yes	Yes		a) No b) Some psychometric properties established (internal consistency and factor analysis)	UK developed and relevant to Australian context	Yes	Very popular in UK. Some agencies, eg. MIF and Ballarat Centrelink using it. However domains remain contested.

			Possible Criteria for	Rating SERVICE Out	come Measures *		
Outcome Measure	Measures domains directly relevant to the recovery orientation of services ##	Is manageable and easy to use (≤100 items)	Has undergone appropriate development processes and ideally been scientifically scrutinised	Includes a consumer perspective	e) Applicable to Australian context	Acceptable to consumers	Issues for PDRS
REE Recovery Environment Enhancing Measure		No (166 items) however ERFS is a short form of REE that is easy to use.	Only face validity established (no statistical validity). High estimate of reliability established.	Yes (captures consumer view of the recovery orientation of the service)	Yes, pilot study with REE conducted at Mind. Mind received permission to slightly adapt the measure as an Australian version.	Yes	Designed with expectation that consumer researchers will administer rather than staff, so has resource implications. Highly valued by consumers in trials at Mind
Consumer & Carer Satisfaction Surveys	Variable	Variable	Variable	Variable	Tend to be skewed towards positive findings. However, high satisfaction scores can be indicative of quality.	Yes	Adaptable to local needs. Seen to be an adjunct to OM (see <u>http://www.rethink.org/</u> My Experience of the Service 2011 National satisfaction feedback from people using Rethink services )
MHECO 'Experience of the Service' Survey	Yes	Variable	'Proof of Concept' trial is currently underway in relation to a national project	Yes	Yes – developed by a Victorian research team that included consumers and carers	Yes	Adaptable to local needs and seen to provide more detailed information about service delivery and quality than satisfaction questionnaires

\*Adapted from Burgess et al (2008).

## Recovery domains come from Victorian Govt Recovery Framework Report and are; promote culture of hope; promote autonomy and self-determination; collaborative partnerships and meaningful engagement; focus on strengths; holistic and personalised care; family, carers, support people and significant others; community participation and citizenship; responsiveness to diversity; reflection & learning.

# Appendix 2: Mind PARC Exit Survey Based on Rethink Mental illness UK Client Satisfaction Survey (2011)

- 1. I feel that staff in the service have respected me and treated me with dignity.
  - 0 No Comment
  - 1 Strongly Disagree
  - 2 Disagree
  - 3 Agree
  - 4 Strongly Agree

#### 2. I feel that I have been listened to by staff in the service.

- 0 No Comment
- 1 Strongly Disagree
- 2 Disagree
- 3 Agree
- 4 Strongly Agree

#### 3. My cultural and spiritual needs have been met.

- 0 No Comment
- 1 Strongly Disagree
- 2 Disagree
- 3 Agree
- 4 Strongly Agree

#### 4. I have been given relevant and sufficient information about the service.

- 0 No Comment
- 1 Strongly Disagree
- 2 Disagree
- 3 Agree
- 4 Strongly Agree

#### 5. I have been involved in deciding on the support that I have been given.

- 0 No Comment
- 1 Strongly Disagree
- 2 Disagree
- 3 Agree
- 4 Strongly Agree

#### 6. I have been getting the right kind of support from the service.

- 0 No Comment
- 1 Strongly Disagree
- 2 Disagree

- 3 Agree
- 4 Strongly Agree

#### 7. The service has supported me towards achieving my goals.

- 0 No Comment
- 1 Strongly Disagree
- 2 Disagree
- 3 Agree
- 4 Strongly Agree

#### 8. I feel safe and comfortable in the physical environment of the service.

- 0 No Comment
- 1 Strongly Disagree
- 2 Disagree
- 3 Agree
- 4 Strongly Agree

#### 9. I have taken an active role to influence how the service is run.

- 0 No Comment
- 1 Strongly Disagree
- 2 Disagree
- 3 Agree
- 4 Strongly Agree

#### 10. If I had a similar need for support in the future, I would use the service again.

- 0 No Comment
- 1 Strongly Disagree
- 2 Disagree
- 3 Agree
- 4 Strongly Agree

#### 11. What has been the most helpful thing about your stay at PARC?

#### 12. If you could change something about PARC what would it be?

#### 13. Any other comments and feedback?

Thank you for your feedback. It will help us to improve our service.

# Appendix 3: Mind SA Satisfaction Survey (2010)



# Mind South Australian Client Satisfaction Survey 2010

Thank you participating in this survey. The aim of it is to hear how you feel about Mind services, and provide Mind with feedback that can improve our services.

Please answer questions using the following scale:

Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
SA	А	Ν	D	SD

#### A. OVERALL SATISFACTION

#### Q.1A

I am satisfied with the support provided to me by Mind staff.	SA	А	Ν	D	SD

#### Q.2A

Mind services support me in my recovery.	SA	Α	Ν	D	SD

#### Q.3A

My care plan has been developed with my input.	SA	А	Ν	D	SD

#### Q.4A

I am satisfied with how my Mind Worker responds to my	SA	Α	Ν	D	SD
needs.					

#### **B. INDIVIDUAL OUTCOMES**

# Q.1B

I deal more effectively with day to day issues.	SA	Α	Ν	D	SD

## Q.2B

I am better able to manage my mental health.	SA	Α	Ν	D	SD

#### Q.3B

I am more able to deal with difficult situations.	SA	А	Ν	D	SD

## Q.4B

My housing situation has improved.	SA	Α	Ν	D	SD

#### Q.5B

Mind staff have supported me to link with employment	SA	А	Ν	D	SD
assistance.					

## Q.6B

Mind staff have supported me to link with education	SA	Α	Ν	D	SD
assistance.					

## Q.7B

My involvement in my surrounding community has	SA	А	Ν	D	SD
improved.					

#### **C. PARTNERSHIP EFFECTIVENESS**

#### Q.1C

I have met with my Mind Worker and Key Worker together	SA	Α	Ν	D	SD
to discuss my needs.					

## Q.2C

I am aware that my Mind Worker and Key Worker discuss	SA	Α	Ν	D	SD
how to meet my needs.					

#### Q.3C

I feel involved in decisions made by my Mind Worker with	SA	Α	Ν	D	SD
my Key Worker.					

#### 4. GENERAL FEEDBACK

4.1 What do you like best about the service you receive from Mind?

4.2 What do you like least about the service you receive from Mind?

4.3 How could the service you receive from Mind be improved?

4.4 Do you have any other comments or suggestions about Mind services?

Thank you for taking the time to participate in this questionnaire.

# Appendix 4: WHOQoL

mino		_			
rebuild-reconnect-rediscover l					
WORLD HEALTH ORGANISATIO		_			
NOTE: Before asking clients to complete INSTRUCTIONS, a copy of which is ava			have read the doc	ument WHOQO	L ADMINISTRATION
COVER SHEET Please enter the relevant data into the		d for each some			
DATE OF QOLQ is the date the WHO Q MIND PROGRAM NAME is the name of MIND UCN is the 4 digit Unique Client N SUPPORT WORKER is the name of the	f the program in v lumber assigned	which client was to each client up	participating at time oon engaging with I	Mind.	
DATE OF QOLQ (dd / mm / yyyy):					
MIND PROGRAM NAME:					
MIND UCN:					
SUPPORT WORKER:					
	w	HOQOL-BRE	F		
		HOQOL-BRE n Version (Ma			
	Australia				
This assessment asks how you feel about yo unsure about which response to give to a qua response. Please keep in mind your standards, hopes, j	Australia Ir our quality of life, he estion, please choo	n Version (Ma astructions waith, & other area use the one that a	ay 2000) s of your life. Please opears most appropri	ate. This can ofte	1 be your first
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1			4	5
	2	2		
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	2	3	4	5
Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
Not at all	Slightly	Somewhat	To a great extent	Completely
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
Not at all	Slightly	Moderately	Very	Extremely
1	2	3	4	5
-	Not at all 1 1 1 1 1 1 Not at all	Not at all     Slightly       1     2       1     2       1     2       1     2       1     2       1     2       1     2       1     2       Not at all     Slightly	Not at allSlightlySomewhat123123123123123123Not at allSlightlyModerately	Not at allSlightlySomewhatTo a great extent12341234123412341234123412341234Not at allSlightlyModeratelyVery

mind						
rebuild · reconnect · rediscover life						
QUALITY OF LIFE QUESTIONNAIRE The following questions ask you to say how goo various aspects of your life over the <u>last two we</u>	-	ou have felt ab	out			
	Very Dissatisfied	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied	WORL
16. How satisfied are you with your sleep?	1	2	3	4	5	
17. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5	WORLD HEALTH ORGANISATION QUALITY OF LIFE QUESTIONNAIRE
18. How satisfied are you with your capacity for work?	1	2	3	4	5	JKGAN
19. How satisfied are you with yourself?	1	2	3	4	5	Ac
20. How satisfied are you with your personal relationships?	1	2	3	4	5	
21. How satisfied are you with your sex life?	1	2	3	4	5	
22. How satisfied are you with the support you get from your friends?	1	2	3	4	5	
23. How satisfied are you with the conditions of your living place?	1	2	3	4	5	
24. How satisfied are you with your access to health services?	1	2	3	4	5	
25. How satisfied are you with your transport?	1	2	3	4	5	
	Never	Infrequently	Sometimes	Frequently	Always	
How often do you have negative feelings 26. such as blue mood, despair, anxiety, depression?	1	2	3	4	5	POKM
i	nk you for comp	oleting this Que	stionnair <del>e</del> .			FURM NU. 24 PAGE 3

# **Appendix 5: CANSAS**

CANSAS (Camberwell Assessment of Need Short Appraisal Schedule)	
Please tick when the questionnaire was completed:	
On entry to our service o 6 months	s 🛛 12 months
□ 18 months □ 24 mont	hs on exit of our service
The CANSAS measures met and unmet needs and is used to people can experience difficulties. The CANSAS is a very goo	identify potential areas of support in a range of life areas in which Id starting point for developing a recovery plan.
As we go through this assessment it is important for the inte	
<ul> <li>This is not a test – There are no right</li> </ul>	t or wrong answers.
<ul> <li>There is no time limit.</li> </ul>	
	s will not affect your access to the service.
<ul> <li>Your answers relate to your percept</li> </ul>	
<ul> <li>The questions are about any proble</li> </ul>	ms you have had in the last month.
The CANSAS is designed to be interviewer administrated and	d upon being asked each question you need to give
each question a rating.	
The ratings are as follows:	
RATING	
This area is not a serious problem for me at all (no need)	0
This area is not a serious problem for me because of help I	am 1
given (met need)	
This area remains a serious problem for me despite any he	pl 2
am given (unmet need)	
I do not want to answer this question/Not known	9

PAGE 1 of 2

		Client	Carer	Key Worker	Other	
1.	Accommodation – What kind of place do you live in?					
2.	Food – Do you get enough to eat?					
3.	Looking after the home – Are you able to look after your home?					
4.	Self-Care – Do you have problems keeping clean and tidy?					
5.	Daytime Activities – How do you spend your day?					
6.	Physical Health - How well do you feel physically?					
7.	Psychotic Symptoms – Do you ever hear voices or have problems with your thoughts?					
8.	Information on condition and treatment – Have you been given clear information about your medication?					
9.	Psychological Distress – Have you recently feelt very sad or low?					
10.	Safety to Self - Do you ever have thoughts of harming yourself?		1			
11.	Safety to Others - Do you think you could be a danger to other people's safety?	1				
12.	Alcohol – Does drinking cause you any problems?		Ī			
13.	Drugs – Do you take any drugs that aren't prescribed?		Ĩ			
14.	Company – Are you happy with your social life?					
15.	Intimate Relationships – Do you have a partner?					
16.	Sexual Expression – How is your sex life?		Ī			
17.	Child Care – Do you have any children under 18?		Ī			
18.	Telephone – Do you know how to use a telephone?					
19.	Transport – How do you find using the bus, train or tram?		Ī			
20.	Money – How do you find budgeting for your money?		Ī			
21.	Benefits – Are you getting the money you are entitled to?					
22.	Basic Education - Any difficulty in reading, writing or understanding English?					

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Source: Slade, M., Thomicroft, G., Loftus, L., Phelan, M. & Wykes, T. "Camberwell Assessment of Need" (1999).



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