

# Outcome Measurement of Community Based Mental Health Services in Western Australia

Literature and Concept Summary

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# Literature and concept summary: outcome measurement in community based mental health services in Western Australia

#### 1. Introduction and context

This paper has been commissioned by the Western Australian Association for Mental Health (WAAMH) as a resource to support the development work related to establishing an outcome measurement process for community based mental health services. The report has been prepared by *Inclusion Matters*, utilising personnel with expertise in the areas of outcomes measurement, social inclusion, disability, non government organisational research and an understanding of the WA context.

The paper aims to provide a brief overview of key ideas related to outcome measurement relevant to community based mental health services and their consumers in WA. Due to the breadth of scope of the paper, it is not an extensive or rigorous literature review but provides a scan of the literature that could shape a more thorough literature review in any of the content areas. The paper has been written with the aim of informing the sector of key ideas, issues, concepts and approaches.

The major policy context for the paper is the Commonwealth government's 4th National Mental Health Plan that outlines a vision for service delivery and a range of outcomes and indicators (Commonwealth of Australia, 2009). The Plan offers a broad direction but does not clearly articulate the process for outcomes measurement, nor the levels of responsibility for this. The Plan articulates the broad outcome direction as listed in Table 1.

There are several challenges for the WA context. As with other States and Territories, the WA community based mental health sector is required to build its capacity to engage in the development and implementation of an outcomes measurement approach. The tasks within this are numerous and complex, as discussed in this paper. Additionally, the WA sector is required to do this in a way that is relevant to the diverse needs of its service providers and consumers, including those in rural and remote areas, those from Indigenous and culturally diverse communities, and those working with other unique populations and contexts including farming, fly-in-fly-out mining contexts, and others. This diversity of population, the scale of geographic distance, and the costs associated with service delivery in these contexts add a significant layer of complexity to the sector's task.

Table 1: Summary of priority areas, outcomes and indicators for change in the 4<sup>th</sup> National Mental Health Plan.

NOTES: \* This indicator requires further development

Priority area	Outcomes	Indicators for monitoring change
Priority area Social inclusion  Prevention and early intervention	Outcomes  The community has a better understanding of the importance and role of mental health and wellbeing, and recognises the impact of mental illness.  People with mental health problems and mental illness have improved outcomes in relation to housing, employment, income and overall health and are valued and supported by their communities.  Service delivery is organised to deliver more coordinated care across health and social domains.  People have a better understanding and recognition of mental health problems and mental illness. They are supported to develop resilience and coping skills.  People are better prepared to seek help for themselves, and to support others to prevent or intervene early in the onset or recurrence of mental illness.  There is greater recognition and response to co-occurring alcohol and other drug problems, physical health issues and suicidal behaviour.  Generalist services have support and access to advice and specialist services when needed.	<ul> <li>Indicators for monitoring change</li> <li>Participation rates by people with mental illness of working age in employment</li> <li>Participation rates by young people aged 16–30 with mental illness in education and employment</li> <li>Rates of stigmatising attitudes within the community *</li> <li>Percentage of mental health consumers living in stable housing *</li> <li>Rates of community participation by people with mental illness *</li> <li>Proportion of primary and secondary schools with mental health literacy component included in curriculum</li> <li>Rates of contact with primary mental health care by children and young people</li> <li>Rates of use of licit and illicit drugs that contribute to mental illness in young people</li> <li>Rates of suicide in the community</li> <li>Proportion of front-line workers within given sectors who have been exposed to relevant education and training *</li> <li>Rates of understanding of mental health problems and mental illness in the community *</li> <li>Prevalence of mental illness *</li> </ul>
Service access, co- ordination and continuity of care	There is improved access to appropriate care, continuity of care and reduced rates of relapse and re-presentation to mental health services.  There is an adequate level and mix of services through population-based planning and service development across sectors.  Governments and service providers work together to establish organisational arrangements that promote the most effective and efficient use of services, minimise duplication and streamline access.	<ul> <li>Prevalence of mental liness *</li> <li>Percentage of population receiving mental health care</li> <li>Readmission to hospital within 28 days of discharge</li> <li>Rates of pre-admission community care</li> <li>Rates of post-discharge community care</li> <li>Proportion of specialist mental health sector consumers with nominated general practitioner *</li> <li>Average waiting times for consumers with mental health problems presenting to emergency departments *</li> <li>Prevalence of mental illness among homeless populations *</li> <li>Prevalence of mental illness among people who are remanded or newly sentenced to adult and juvenile correctional facilities *</li> </ul>
Quality improvement and innovation	The community has access to information on service delivery and outcomes on a regional basis. This will include reporting against agreed standards of care including consumer and carer experiences and perceptions.  Mental health legislation meets agreed principles and, in conjunction with any related legislation, is able to support appropriate transfer of civil and forensic patients between jurisdictions.  There are explicit avenues of support for emerging and current leaders to implement evidence-based and innovative models of care, to foster research and dissemination of findings, and to further workforce development and reform.	<ul> <li>Proportion of total mental health workforce accounted for by consumer and carer workers</li> <li>Proportion of services reaching threshold standards of accreditation under the <i>National Mental Health Standards</i></li> <li>Mental health outcomes for people who receive treatment from state and territory services and the private hospital system</li> <li>Proportion of consumers and carers with positive experiences of service delivery *</li> </ul>
Accountability  – measuring and reporting progress	The public is able to make informed judgements about the extent of mental health reform in Australia, including the progress of the Fourth Plan, and has confidence in the information available to make these judgements.  Consumers and carers have access to information about the performance of services responsible for their care across the range of health quality domains and are able to compare these to national benchmarks.	Proportion of mental health service organisations publicly reporting performance data *

# 2. Definitions – understanding the outcomes measurement vocabulary

# Defining 'outcome'

In general, outcomes measurement literature discusses the importance of distinguishing between outcomes (for recipients of services), processes (including practices and processes used to deliver services) and outputs (usually quantitative measures of the extent of service delivery).

The literature set of outcome measurement is a large one and is made more difficult to understand by a variety of terminology in use. In particular, there is conceptual confusion between the notions of 'outcome', 'success measures', 'performance indicators', and 'quality standards'. The below discussion will attempt to clarify these terms.

# An outcome is:

'the impact of the service on the status of individuals or a group' (Steering Committee for the Review of Government Service Provision, 2004: p.xxiii-xxiv).

In a general sense, if outcomes are understood as the 'result of an action or a process' (WAAMH, 2010, p.2), then outcomes can be observed at a range of levels. Within human services, outcomes are often discussed in relation to:

- Individual service recipients / consumers;
- Communities community members and organisations (i.e. broader change in the community / society);
- Services and service systems.

Each of these areas is referred to in the 4<sup>th</sup> National Mental Health Plan, though the terminology used and the ordering of discussion about them is not consistent.

## **Outcomes for individuals**

The 4<sup>th</sup> National Mental Health Plan identifies the importance of measuring the outcomes for individuals, that is, for 'people with mental health problems and mental illness'. Outcomes for individuals are also sometimes called 'consumer outcomes' (Penrose-Wall, 2006; WAAMH, 2010). The NSW Mental Health Coordinating Council defines these as:

'the effect on a patient's [consumer's] health status that is attributable to an intervention'

(Andrews et al 1994:12 quoted in Penrose-Wall, 2006 p. iii).

WAAMH (2010) identifies that outcomes for individuals can be understood as 'demonstrable improvements

in the lives of people' (p.5). These definitions show a breadth of scope in regard to what might be the

outcome focus, ranging from 'whole of life' outcomes to changes in 'health status'. This breadth of potential

outcome focus is common in human services. For example, outcomes for individuals or recipients of human

services frequently include such outcome concepts as quality of life, social inclusion, or independence, as

well as the attainment of individual life goals (for example, getting a driver's licence, a job, or having a

holiday).

While the primary focus in most mental health literature is on outcomes for people with mental health

problems or illness, some texts also include a focus on outcomes for the families and carers of these

individuals.

**Outcomes for communities** 

A role of many human services is to bring about broader community and social change. Some services focus

on this more than others. This is an emerging area of outcome measurement. Some of the work in this arena

is conducted by social researchers (for example, those conducting studies on changes in community

attitudes over time), as well as market researchers (for example, those seeking to determine the extent to

which a human service is known and respected in the community). A significant problem in this area is the

attribution of causation, that is, the extent to which it is evident that a human service has directly brought

about some element of community change, given that many factors affect changes in the broader

community.

The 4<sup>th</sup> National Mental Health Plan identifies a number of outcomes at the level of community, discussed in

Section 5. In addition, the Plan identifies that no existing data sources are available to monitor many of

these proposed community outcome areas, or that data collection requires large scale population based

data collection which is both difficult and expensive (see Commonwealth of Australia, 2009: Appendix 2).

Outcomes at the level of services

In addition, the 4<sup>th</sup> National Mental Health Plan also identifies the need to report on a range of service

provision processes and practices. Within the human services, processes are understood to be the 'ways in

which program services and goods are provided' (Horsch, 2005 cited in Quilliam & Wilson, 2011, p. 5).

In general, a range of terminology is used in the literature for this area of focus. The NSW Mental Health Co-

ordinating Council refers to 'process outcomes' defined as:

'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)' (Penrose-Wall, 2006, p.iii).

The NSW Mental Health Co-ordinating Council further explains that 'processes of care ... account for how the

organisation performs, rather than how the consumer changes over time' and argues that it 'is the most

relevant data for quality improvement of systems of care' (Penrose-Wall, 2006, p.xiv). As discussed in the

NSW report, process measures are a key feature of quality improvement systems.

The WA Association for Mental Health also adopts this definition, referring to this focus as 'organisational or

process outcomes' (WAAMH, 2010).

Within the human services sector, this area can include both service delivery process measures (sometimes

linked to performance or quality standards), as well as a focus on measuring the achievement of sector wide

change. Service delivery process measures are frequently a mix of identified 'best practice' elements (such as

family or person centred practice), and broader values (often linked to human rights notions) about how

services treat their consumers. By contrast, sector wide 'outcome' measures typically include a focus on

practice and structural changes, such as co-ordination across service areas, and streamlined service delivery.

The Council on Quality and Leadership (2010) in the USA make a clear distinction between process measures

(what they refer to as 'success indicators', that is 'indicators that characterise excellence in person-centred

supports' p. 4) and service 'standards'. Process indicators are part of a quality improvement system, whereas

standards measure compliance with regulations or organisational requirements. Again, this terminological

distinction is important. Process measures are more aspirational based on constantly evolving

understandings of what is a best practice approach in the field. Standards are usually absolute requirements

that must be demonstrated to be met, and often represent minimum levels of achievement. In many

instances, standards are set by government funders.

#### Conclusion

A range of terminology is used in the area of outcome measurement. In general it is useful to maintain the distinction between 'outcomes' as results of services (usually focused on consumers of services), and 'processes' or organisation/process outcomes which focuses on the practices and processes used to deliver services within an agency or across a sector.

Much of the literature combines a focus on these two elements. The 4<sup>th</sup> National Mental Health Plan combines this focus and discusses both outcomes (for individuals and communities) and well as organisational/process outcomes under most priority areas.

# 3. Developing outcome measures in the human services sector

## Steps of the process

According to the Australian Bureau of Statistics (ABS), any framework for measuring outcomes in the human services requires:

- 1. Deciding the desired areas of individual or community change (i.e. desired outcomes);
- 2. Defining these areas and their parameters (eg. if 'recovery' or 'social inclusion' is important, how do we define these concepts?);
- 3. Identifying the indicators of these changes by making 'pragmatic decisions about what phenomena will provide the greatest insight into these issues';
- 4. Deciding how these phenomena can be measured; and
- **5.** Combining and presenting the resulting information in a clear and informative way (ABS, 2001, ch. 1).

All of these steps are complex and are likely to include significant healthy disagreement amongst stakeholders. Among the issues influencing the decisions are cultural considerations. As Bhui and Dinos note, culture is linked to the way mental distress and social problems are perceived and experienced (2008: 411) and therefore cultural considerations will shape the definition of the outcome. This is particularly relevant to the WA context given the significant proportion of Indigenous and other cultural groups within the population, and the diverse understandings these populations have of mental health.

The complexity of the process of pursuing the above steps in the community based mental health sector, is evidenced by the Australian Mental Health Outcomes and Classification Network (2011) report *Development* 

of a consumer self-report measure that focuses on the social inclusion aspects of recovery. This report records the divergent views of stakeholders attempting to define and measure social inclusion, and evidences the difficulty of engaging in steps 1 - 5 above.

#### **Selecting indicators**

Once outcomes are named, agreed upon and defined, then step 3 above (ABS, 2001) identifies the need to determine 'indicators' of these outcomes. In general, indicators are observable or recordable elements that evidence an outcome has been achieved. For example, if an outcome of service delivery is stable housing, then one indicator that might evidence this would be the number of consumers moving from emergency housing to longer term housing. The selection of indicators is itself a complex task, as stakeholders determine the many items that might evidence change, and select between these. Indicators might include perceptions, behaviours or conditions that indicate the existence of the outcome or a definitional sub domain of the outcome (Schalock, 2004).

According to researchers in the area of outcomes measurement, indicators should be chosen with the following considerations in mind:

**Focus/ Validity:** Does the indicator enable one to know about the expected result or condition? Does

it measure what is intended?

**Reliability:** Is the indicator defined in the same way over time? Are data for the indicator

collected in the same way over time? Is it consistent across people or raters?

**Timing:** What intervals of measurement are most useful to decision makers and will data be

available?

**Resourcing/useability:** Are data currently being collected? If not, can cost/resource effective instruments

for data collection be developed?

Resonance/credibility: Is this indicator important to most people? Will this indicator provide sufficient

information about a condition or result to convince both supporters and sceptics?

**Quantification:** Is the indicator quantitative as this often provides the most useful information to

decision makers, though qualitative indicators may be required to describe some

outcome phenomena?

**Sensitivity** Is the indicator sensitive to the changes expected? Is it worded to pick up range of

change? (Based on Horsch, 2005, Schalock, 2004).

Finally, some indicators require the collection of data directly from stakeholders as opposed to, or to be used together with, the use of more population based data that may be already available. In these cases, it is important to determine who is the primary target for data collection, whose views are important, or even most important. Trauer (2004) notes that routine outcome measurement involves a variety of parties with the two key ones being the clinician and the consumer, arguing that 'the consumer's perspective is considered essential for a comprehensive understanding of outcome' (2004: 48). Trauer notes that there are many obstacles to completion of outcome measures by consumers, including that completion is voluntary, and that the service culture is also significant in whether self-rating assessments are completed. Trauer proposes that 'consumer self-rating is not yet firmly established in the outcomes measurement culture' (2004: 48). Despite these obstacles, there is now a large body of research identifying the inaccuracies of using proxies (i.e. people other than the person concerned) to rate outcomes, and the frequent variation between results provided by proxy (including clinician, family member and service provider) and self report (Schalock, 2004). These results have further fuelled interest in developing appropriate self report measures and data collection instruments appropriate for use by service recipients directly.

This literature shows that there are defined and multiple steps in the process of establishing an outcomes measurement approach in any sector or service. Further detail for organizations is provided in section 7.

# 4. Outcomes for individuals

As described in the ABS framework (2001), the first step is to decide on the outcomes to be measured and secondly, to define them. This section explores two of the major outcome areas pertinent to individuals with mental illness: social inclusion and quality of life. It should be noted that the sector may select these or additional / different outcome areas if consulted.

#### Personal versus clinical outcomes

As described in the Australian Mental Health Outcomes and Classification Network (AMHOCN) 'Social Inclusion Outcome Measure: National Consultation' presentation (n.d.)<sup>1</sup>, the individual's journey of recovery can be understood in both clinical and personal terms. Outcomes for individuals can therefore be measured within a clinical frame of reference, or a more personal, individualised one. Clinical outcomes are usually assessed as part of clinical service delivery and utilise a range of clinical diagnostic and assessment

<sup>&</sup>lt;sup>1</sup> This is found as an appendix in AMHOCN (2011) Development of a consumer self-report measure that focuses on the social inclusion aspects of recovery.

instruments. Some of these are already formally used by the AMHOCN as part of their outcomes measurement process. Currently, the National Outcomes and Casemix Collection (NOCC) utilises a suite of measures designed to assess changes in symptomatology and functioning of individuals rather than personal recovery (Burgess, Pirkis, Coombs, Rosen, 2010:10).

This paper focuses on non-clinical outcomes related to an individual's life circumstances and aspirations. The AMHOCN identifies this outcomes focus as 'personal recovery'. According to the AMHOCN, 'personal recovery' (as opposed to 'clinical recovery') includes elements of social inclusion (employment and social activity), personal ownership, self efficacy, and a narrative of hope (AMHOCN, n.d. slide 4 in AMHOCN, 2011). By contrast, elements included in 'clinical recovery' are rehabilitation (improvements in functioning) and remission (removal of symptoms) (AMHOCN, n.d. slide 4 in AMHOCN, 2011). This distinction is echoed in other AMHOCN literature by Burgess, Pirkis, Coombs, Rosen (2010:4) where the distinction is made between measuring individual recovery and measuring 'reduction in symptomatology or increases in levels of functioning' (p.4).

While not identified by the AMHOCN, outcomes identified as falling within the personal recovery focus are numerous. The overarching vision of the *National Mental Health Policy, 2008*, is to enable Australians with a mental illness to participate meaningfully in society (Commonwealth of Australia, 2009: 22). Such a focus on social participation is broad and requires further unpacking in relation to the outcomes that might be measured for individuals. This is the focus of this section.

## Social inclusion outcomes

The field of social inclusion is a large and diverse one, and includes researchers from academia, human services organisations, government, and policy research institutes. Social inclusion is a concept that is closely related to social exclusion making it difficult to discuss one without discussing the other. They can be viewed as two ends of a single dimension (Australian Institute of Family Studies, 2008: 1).

The 4<sup>th</sup> National Mental Health Plan identifies 'social inclusion and recovery' as one of its priority areas, and includes outcomes relating to greater community understanding of mental health, and outcomes for individuals in being valued, supported and living full lives. Indicators of outcomes are identified as:

- 'participation rates by people with mental illness of working age in employment;
- participation rates by young people aged 16-30 with mental illness in education and employment;
- rates of stigmatising attitudes within the community;

• percentage of mental health consumers living in stable housing;

rates of community participation by people with mental illness.' (Commonwealth of Australia, 2009:

76).

In addition, the Plan identifies several service access outcomes and indicators, particularly relating to access

to mental health care.

The framing of social inclusion and related indicators within the 4<sup>th</sup> National Mental Health Plan is arguably

more narrow than that discussed in the broader literature and in other government policy domains, unless

the final indicator in relation to rates of community participation is taken to have a broad meaning

encompassing political, social, leisure/recreational, cultural and spiritual participation. A discussion of this

broader understanding of the concept of social inclusion is provided below.

There is substantial debate about definitions of social exclusion. Saunders, Naidoo and Griffiths (2007)

adopt the definition devised by a group of British researchers based on a sizeable review of relevant

literature:

'Social exclusion is a complex and multi-dimensional process. It involves the lack or denial of

resources, rights, goods and services, and the inability to participate in the normal relationships and

activities, available to the majority of people in society, whether in economic, social, cultural, or

political arenas. It affects both the quality of life of individuals and the equity and cohesion of society

as a whole' (Levitas et al., 2007: 9 quoted in Saunders, Naidoo & Griffiths, 2007: 12).

This definition highlights that social inclusion is a 'whole of life' concept including people's experiences in

economic, social, cultural, and political arenas of life, among others.

Morgan et al (2007) draw on the work of Parr (2004) to argue that there is a subjective experience to

inclusion, while exclusion can be both material disadvantage and non-material disadvantage based on

discriminatory responses of others and institutions:

'Inclusion denotes relations and practices that people with mental health problems perceive to

signify their positive involvement in and 'mattering' to a local setting ... By contrast 'exclusion'

denotes more negative eventualities that involve rejection, avoidance and distancing from other

community members, such that individuals are 'made different' through more or less deliberate

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social actions reinforcing their problematic mental health status' (Parr et al quoted in Morgan et al, 2007: 480).

At a global level, the Department of Economic and Social Affairs, United Nations, states that social inclusion has been increasingly recognised in recent years and that creating a society for all is a 'moral obligation' (2010: iii). They argue that in measuring aspects of social inclusion at the national and sub-national level, fields to be covered include: economic resources and employment, health, education, affordable access to public services, housing, civil rights, security and justice, well-being, information and communications, mobility, social and political participation, leisure and culture (2010: 45).

The Australian government currently has a social inclusion agenda, managed by the Social Inclusion Board who state that to be socially included people must be given the opportunity to:

- Secure a job,
- Access services,
- Connect with family, friends, work, personal interests and local opportunity,
- Deal with personal crisis, and
- Have their voice heard (Australian Social Inclusion Board, 2008).

The Social Inclusion Board's agenda expresses a 'vision of a socially inclusive society ... in which all Australians feel valued and have the opportunity to participate fully in the life of our society. Achieving this vision means that all Australians will have the resources, opportunities and capability to:

- Learn by participating in education and training;
- Work by participating in employment, in voluntary work and in family and caring;
- Engage by connecting with people and using their local community's resources; and
- Have a voice so that they can influence decisions that affect them' (Australian Government, http://www.socialinclusion.gov.au/).

The European Union (EU) began measuring social exclusion with an initial set of indicators in 2001, which they have since added to and subtracted from. These EU indicators have guided the work of the Australian Social Inclusion Board who identified 33 social indicators grouped under the following 'headline indicators' as a means of measuring social exclusion: poverty and low income, lack of access to the job market, limited social supports and networks, effect of the local neighbourhood, exclusion from services, health and contextual (health and social expenditure per capita).

The Board considers these 'headline indicators' as high level, longer term indicators of the outcomes of

social inclusion: 'They are considered to be the most important outcomes to analyse trends over time to

show whether there has been progress toward achieving social inclusion objectives' (Australian Social

Inclusion Board, 2010: 5).

In devising a series of Australian studies into social exclusion between 2007 and 2009, Saunders, Naidoo &

Griffiths (2007) utilised 27 indicators (later reduced to 26, Saunders & Wong, 2009) of social inclusion across

three core domains identified:

'disengagement – lack of participation in social and community activities;

service exclusion – lack of adequate access to key services when needed;

• economic exclusion – restricted access to economic resources and low economic capacity' (2007, p.

ix).

These domains relate to and, to some extent, synthesise domains suggested by other eminent researchers

(see discussion in Saunders, Naidoo and Griffiths, chapter six, 2007). As such it should be noted that the

domain related to political exclusion/engagement sits inside that of 'disengagement' which captures all

forms of social relations. Their studies surveyed over 2700 Australians randomly selected, as well as 700

clients of community sector welfare services who completed a shortened version of the same survey.

In New Zealand, the Mental Health Commission has recently completed a report on the social inclusion of

people experiencing mental illness and addiction. They identified 14 indicators across 10 life domains.

Domains included: Relationships, Health, Civil participation, Safety, Cultural identity, Leisure and recreation,

Knowledge and skills, Employment, Standard of living and Transport.

The report is based on data from the New Zealand General Social Survey which explores social cohesion in

New Zealand. Over 8000 individuals (a 'scientifically selected sample of households') are surveyed every two

years through face-to-face computer-assisted interviews. Survey topics include: housing, health, life

satisfaction, safety and security, knowledge and skills, social connectedness, human rights, the environment,

and culture and identity (Statistics New Zealand, 2011).

This echoes a host of other research studies. In this sense, work on developing measurement approaches for

social inclusion is well progressed and there are significant resources to draw on. In addition, there is

significant work undertaken around the measurement of other related and over-lapping concepts such as

'participation', and 'community involvement', among others. The key sub domains of social inclusion, as discussed in this literature review, are summarised below in Table 2. It should be noted that, in many instances, these domains encompass a range of areas or sub domains not shown in the table.

Table 2: Summary of sub domain concepts discussed, within the definition of social inclusion

Saunders et al (2007)	NZ Mental Health Commission (Statistics New Zealand, 2011)	Aust Social Inclusion board vision (www.socialinclusion.gov. au)	EU based Aust Social Inclusion Board headline indicators Aust Social inclusion Board, 2010)	4 <sup>th</sup> National Mental Health Plan – social inclusion indicators (Commonwealth of Australia, 2009)
Economic exclusion	Employment	Employment	Access to job market	Participation in employment
			Poverty and low income	
	Knowledge and skills	Participating in education and training		Participation in education and training
Disengagement	Relationships	Voluntary work	Limited social supports and networks  Effect of local neighbourhood	Community participation
		Family/caring roles		
	Civil participation	Coping with crisis		
		Connecting with people		
		Voice heard		
	Safety			
	Cultural identity			
	Leisure and recreation			
Service		Access services		
exclusion	Health		Health	
	Standard of living			Living in stable housing
	Transport			

Within the mental health sector, additional work exists that specifically targets the area of measuring social inclusion.

A UK article by Morgan et al (2007) reports on a review of mental health and social exclusion studies. This provides a useful summary of available existing approaches. Morgan et al found only eight studies that attempted to quantify social inclusion using questionnaires designed specifically to measure social inclusion using indicators across a number of domains (2007: 481), while other studies relied on available data (eg. case records, notes, questionnaires designed to measure other concepts). Two key studies they reviewed (Dunn, 1999; and Parr et al, 2004), used qualitative methods to explore the relationship between mental health problems and social exclusion. Parr et al argue for the need to look beyond indicators and instead

focus on individuals' experiential processes for 'in this account, social exclusion is subjectively experienced, relative and changeable; it is not a state that can be measured' (Morgan et al, 2007: 481). The authors argue that measures of social exclusion require both objective indicators and subjective experiences (2007: 482).

In the United States, Segal et al, (2011) recently published a study that sought to determine service effectiveness of consumer operated community mental health services, assessing - among other things - social integration. They used the Independent Social Integration Scale (ISIS) which measures five dimensions: social presence, access, participation, production and consumption behaviours. The authors note that the scale possesses high internal consistency and has independently established validity (Segal et al, 2011).

Similarly, a study in the Netherlands focused on social participation outcomes of clients, based on a recent project that sought to widen clients' social networks. Clients were measured in relation to the degree of loneliness they felt and the number of contacts they had. Contact categories such as partner, family, friend, neighbour etc., were established with the number of contacts recorded for clients at baseline and end measurement. Clients were also measured using a scale of 1-11 to determine the degree of loneliness. There is little indication as to the 'quality' of the contacts nor the types of activities engaged in within those networks. Interviews were conducted in which clients were encouraged to define their perception of sociality. The authors endorse that an individual approach to what is meant by social participation is important (Broer et al, 2010).

In Australia, Kightley et al (2010: citing the work of Trauer, 2008 and Patterson et al, 2006) state that 'few or no mental health services are attaining the criterion level of data collection' (2010: 169). What studies there are have used scales such as the Abbreviated Life Skills Profile-16 (LSP-16), the Health of the Nation Outcome Scale (HoNOS), and the Activity and Participation Questionnaire (APQ6).

The LSP-16 measures the level of community functioning over an assessment period. It includes self-care, anti-social, withdrawal and compliance domains. The LSP-16 requires an evaluator to complete and was used by Kightley et al (2010) in their study of 31 mental health service clients, concluding, amongst other things that routine data collection is still difficult to achieve and that non government organisations are wary of outcome measures that may be seen as a bureaucratic exercise that doesn't meet consumer needs (Kightley, 2010). Habibis et al (2002) utilised the LSP-16, along with other tools such as the Global Assessment Scale, to assess a hospital-based mental health service, measuring outcomes for social functioning and social problems. Domains included living situation, accommodation, main source of income, work rehab/training, difficulties with family, loneliness, alcohol and cannabis consumption, satisfaction with

things done, and coping in the community. The authors concluded, among other things, that a 12 month measurement period may not be long enough for improved outcomes to occur and that 'a longer period of time might have produced different results' (Habibis, 2002).

The HoNOS scale is a clinician-completed measure designed to assess 12 domains of health and social functioning over the past fortnight, though there is also a self-rating version. Domains relating to social inclusion include: problems with relationships, problems with activities of daily living, problems with living conditions, and problems with occupation and activities. Each item is rated on a five point scale of severity. An Australian study by Gallagher and Teesson (2000) found that the HoNOS 'performs well' as a routine measure of mental health outcome. 'Case managers indicated that the HoNOS addressed areas of importance and was brief and easy to complete' (Gallagher and Teesson, 2000: 852). Conversely, the scale was also used in an Australian study by Stedman at el (2000) who noted that consumers and service providers expressed concerns including:

- The burden placed on services with the use of outcome data collection measures, and
- The attribution of change with consumers expressing 'misgivings about change being automatically attributed to service interventions' (2000: 848).

The Activity and Participation Questionnaire (APQ6) is an Australian developed questionnaire focusing on the extent of vocational, educational and social participation over a one week period for adult consumers of ambulatory mental health services (Stewart et al, 2010). The rationale for its development is that vocational and social participation is the focus of mental health policy, and none of the routinely used data collection tools (including the HoNOS, the Life Skills Profile, the Kessler 10 Plus, the Behaviour Symptom Identification Scale 32, and the Mental Health Inventory) provide direct measures of these. The APQ6 includes items relating to level of employment, whether seeking work, extent of unpaid work, participation in education and training, and a small subset of social capital related items deemed to measure social and community participation. These items included: visiting relatives or friends, going to a restaurant or club, church activities, performing arts group, art or craft group, sport or physical activity, or other special interest group. Following analysis of data from two trials of the tool (NSW and QLD), an additional item relating to internetbased social activity was added to the social participation set (Stewart et al, 2010). The trials identified good reliability of the tool whether delivered in a self report mode or via phone interview (predominantly for rural consumers), though reliability of items relating to social participation was markedly lower than for other areas of the tool. Data generated by the tool includes an aggregated report on percent of consumers in employment, unpaid work, education or training, and total number of hours of social participation per week (Stewart et al, 2010).

The APQ6 has been utilised by the Australian Mental Health Outcomes and Classification Network (AMHOCN TSD) as part of their mandate to develop a consumer self report measure that focuses on aspects of social inclusion and recovery. A Technical Advisory Group has been involved in the development of the measure, now known as the Life in the Community Questionnaire (LCQ). The basis of this work has been consultation in regard to the adoption of the APQ6 including discussion regarding its ease of use, usefulness and anything that may be lacking from a clinician or consumer perspective when considering social inclusion and personal recovery. AMHOCN also sought feedback about the measure across the broader mental health sector. The consultation report identifies a range of issues with the questionnaire (AMHOCN, 2011). Unfortunately, it appears that the AMHOCN selection of the APQ6, now the LCQ, was not founded on a review of existing social inclusion studies, theories or instruments, nor a detailed set of criteria by which to judge their efficacy. This is divergent from the approach of the AMHOCN when developing clinical outcome measures, which were based on rigorous literature review and analysis (see for example, Burgess et al 2010, Campbell-Orde et al 2005). This is a limitation of existing work by the AMHOCN as it has not commenced from a full review of available approaches. The work is currently ongoing (AMHOCN, 2011).

Overall, as discussed above, some work has been undertaken in the mental health sector to define the sub domains of social inclusion and develop or adapt data collection methods for its measurement. Despite the work reported above, there are few studies in the field of mental health that directly measure social inclusion. In addition to those discussed above, a further set of studies include a focus more on *satisfaction* with various aspects of social life but do not aim to directly measure social inclusion. These therefore provide an additional insight into possible ways of considering domains and measurement broadly related to social inclusion. These are summarised in the Appendix 1.

# **Quality of life outcomes**

As with the concept of 'social inclusion', the concept of 'quality of life' (QOL) is associated with various definitions and includes a range of sub domains that are thought to comprise personal wellbeing (Schalock, 2004). Quality of life (QOL) measures have been used internationally and across cultures in a range of ways by various researchers to assess the quality of life of people. QOL is considered to encompass the array of life experiences (Perry & Felce, 2003). The primary reason for applying QOL measures is to assess how different aspects of a person's life impact on their well-being. Additionally, service organisations attempt to draw upon the tool as an indicator of how they have supported individuals and hence, increased their quality of life (DHWA 2008).

QOL has some conceptual overlap with the concept of social inclusion, as seen in the discussion below. Schalock (2004) proposes that the 125 sub domains of QOL identified in a sub set of literature he analysed can be reasonably amalgamated into eight core domains of QOL. Additionally, he identifies the three most common indicators used in the literature for each domain (analysing 897 articles).

Table 3: Core indicators and descriptors per core quality of life (excerpt from Schalock, 2004: 206)

Core QOL domain	Indicators and descriptors	
Emotional well-being	Contentment (satisfaction, moods, enjoyment)	
	Self-concept (identity, self-worth, self esteem)	
	Lack of stress (predictability, control)	
Interpersonal relations	Interactions (social networks, social contacts)	
	Relationships (family, friends, peers)	
	Supports (emotional, physical, financial, feedback)	
Material well-being	Financial status (income, benefits)	
	Employment (work status, work environment)	
	Housing (type of residence, ownership)	
Personal development	Education (achievements, status)	
	Personal competence (cognitive, social, practical)	
	Performance (success, achievement, productivity)	
Physical well-being	Health (functioning, symptoms, fitness, nutrition)	
	Activities of daily living (self-care skills, mobility)	
	Leisure (recreation, hobbies)	
Self-determination	Autonomy/personal control (independence)	
	Goals and personal values (desires, expectations)	
	Choices (opportunities, options, preferences)	
Social inclusion	Community integration and participation	
	Community roles (contributor, volunteer)	
	Social supports (support network, services)	
Rights	Human (respect, dignity, equality)	
	Legal (citizenship, access, due process)	

Within the life domains, a plethora of measurement scales have been developed and are used to measure one or a variety of features such as satisfaction, happiness, impact of mental illness, level of opportunities, initiative, attainment, level of functioning and symptoms. QOL tools are either conducted through an

interview process or they are self administered and in some cases, assistance from a family member or carer is provided if required (adapted from Tansella & Thornicroft, 2001 in DHWA, 2008).

Different formats have been used to assess quality of life that have involved using subjective or objective measures but researchers are more commonly utilising a combination of the two (Verdugo et al., 2005). Dilemmas arise from relying solely on subjective or objective measures and will be discussed in more detail below, and Cummins (2005) argues that it is important to understand the distinction between them.

Subjective well-being tools measure self-reported happiness and well-being across different aspects of an individual's life (Perry & Felce, 2003). A major tool in both the Australian and international context is the Personal Wellbeing Index (International Wellbeing Group, 2006). The tool is based on a conceptualisation of wellbeing of comprised of eight domains: standard of living; personal health; achieving in life; personal relationships; personal safety; community-connectedness; future security; spirituality-religion (International Wellbeing Group, 2006). It measures the self assessed satisfaction of individuals in each of these domains. A second commonly used tool is that developed by the World Health Organisation, which has versions in many languages and is purported to have wide cultural relevance. An Australian version of the WHO-QOL is available (Murphy et al, 2000). The WHO-QOL is based on six domains: physical health; psychological health; level of independence; social relationships; environment (including safety, home, work, financial, health and social care, recreation and leisure, transport, skills development); and spiritual domain (Murphy et al, 2000).

The main criticism of subjective approaches to QOL measurement arises from various findings that suggest people living with a mental illness, disability, or experiencing impoverished circumstances are reportedly as happy as other groups that have access to more resources and opportunities (LeRoy et al., 2004). Resilience within oppressed and disadvantaged groups to adapt to their constantly challenging environment is one theory raised by Amartya Sen that suggests why the results are skewed (cited in Emerson et al., 2009; Emerson, n.d.; LeRoy et al., 2004). Similarly, Cummins et al (2003) argue that humans are set largely at a default position of wellbeing and have a homeostatic system that maintains equilibrium even throughout most change. Linked to this is the criticism that QOL tools have limited ability to identify changes in QOL states over time.

Objective well-being tools rate people's circumstances according to pre-determined questions that are then compared with other population groups. Examples of questions may incorporate the family's income, material assets or level of education obtained.

# Short summary of some approaches used in human services sector to measure QOL

A range of QOL tools have been used within the clinical and community mental health sector (DHWA, 2008). Though too numerous to address adequately here, these include such tools as the Quality of Life Interview (QOLI) (Lehman, 1998) and the Quality of Life Enjoyment and Satisfaction Questionnaire (Q\_LES\_Q) (Endicott et al, 1993), both developed in the USA. Western Australian developed tools include UWA's unpublished Continuity of Life Inventory (COLI) and Mirabooka Mental Health Service's Client Evaluation Form. In 2008, a range of QOL tools were examined by the Department of Health Western Australia to determine appropriate tools for use in clinical and recovery related services. Two tools were selected as appropriate for the Western Australian context, that being the Manchester Short Assessment of Quality of Life (MANSA) and the Satisfaction Survey for Mental Health Rehabilitation and Recovery Services (DHWA, 2008).

As the notion of outcomes becomes increasingly important to organisations committed to people with a mental illness, QOL methodology has developed notoriety in capturing outcomes that focus on the individual's whole of life, through approaches such as person centred planning (Verdugo et al. 2005). Person centred QOL tools complement flexible and individualised service provision (CQL, 2010). While not a tool explicitly related to theories of wellbeing, the Personal Outcomes Measures (POMs) tool is relevant to this discussion as it seeks to measure across three broad domains (my self, my world, my dreams) and includes 21 outcome measures, many showing direct relationship to established wellbeing sub domains:

- People are connected to natural support networks
- People have intimate relationships
- People are safe
- People have the best possible health
- People exercise rights
- People are treated fairly
- People are free from abuse and neglect
   People experience continuity and security
- People decide when to share personal information
- People choose where and with whom they live
- People choose where they work

- People use their environments
- People live in integrated environments
- People interact with other members of the community
- People perform different social roles
- People choose services
- People choose personal goals
- People realize personal goals
- People participate in the life of the community
- People have friends
- People are respected (CQL, 2007).

The POMs is administered through an interview with the consumer who is asked to estimate the extent to which each outcome area is present in their life (CQL, 2007). The POMs has been used at least once in Australia by the Victorian Department of Human Services in a small evaluation project of disability services. It was not considered viable for use in the state-wide evaluation of services due to cost implications (AHA, 2009).

#### Conclusion

Both the concepts of social inclusion and quality of life have much in common as wide ranging, whole of life concepts comprised of many sub domains. As such, they are likely to have broad relevance to the self-identified and diverse goals of mental health service consumers, that traverse multiple life areas and aspirations. A plethora of data collection instruments exist in both fields, with some specific to mental health.

In general, critical discussion in these fields centres around:

- Whether concept definitions and data collection instruments capture an adequate range of domains (eg cultural, spiritual or political life areas, as well as economic and social);
- Whether data collection instruments are using an appropriate and reliable scale of measurement (eg. how often, level of satisfaction with, level of difficulty with, presence of... etc);
- Whether data collection instruments are able to capture change, especially small changes in shorter time frames.

Another element to this critique, is the extent to which any data collection process in this broad area can both capture change AND attribute the change to the delivery of a human service or intervention. Specifically, the quandary is centred around the fact that if changes are recorded on an individual's QOL or social inclusion scale, how much of that change can be directly or indirectly attributed to the interaction with the service, given many factors interplay in a person's life alongside the service intervention and supports? The ripple effect of the outcomes, changed attitudes and the depth of relationships may very well extend beyond the service's knowledge and direct involvement in the initial work. Given that organisations across the human service sector are frequently working closely together, how much of the outcomes can a community mental health service claim to be a result of their work, as opposed to the work of other service providers? For example, if a family has strengthened their networks and coping mechanisms, how do we know if it is due to their inner resolve and determination, other (informal or formal) resources in their lives or it is due to the connection, support and information provided by one of many organisations?

These questions and other possible contextual limitations require careful reflection during the assessment and application of suitable outcomes measurement approach.

# 5. Outcomes for community

Advocacy efforts towards social change by the community based mental health sector are of vital importance. Work in the sector broadly encompasses stigma and attitude change (HM Government, 2011; MHS, 2010) along with tackling the broader determinants of mental health and mental illness such as poverty, housing and social protection (Henderson et al, 2011). The HM Government's *No Health Without Mental Health* measures their objective of 'Fewer people will experience stigma and discrimination' through a combination of population surveys and gathering direct experiences of employers and people with mental health problems or a mental illness (2011). In addition, the report proposes an annual Attitudes Survey, though these measurement strategies are yet to be implemented (HM Government, 2011). A range of general population attitude surveys have been conducted in both Australia and overseas, which could be used as a starting point for further work (see for example Yazbeck et al, 2004; National Disability Authority, 2007).

Measuring the outcomes of this work is extremely difficult. Within the literature provided, there is no known evidence that work towards social change by mental health services is making a difference to the community due to the difficulty in pin pointing determinants for change (Commonwealth of Australia, 2009:76). Mental health services' efforts would most likely be one factor in a number of elements that create change.

Potential methods for capturing mental health services' impact upon social change may include small scale and large scale outcomes based inquiries. The implementation of small and focused qualitative studies on outcomes within particular communities where the work is based could potentially capture the level of attitude or stigma, for instance. Large scale inquiry would include population surveys. The 4<sup>th</sup> National Mental Health Plan suggests that amendments are needed within the National Minimum Data sets to capture rates of 'stigmatising attitudes' (Commonwealth of Australia, 2009:76). Regardless of the size and method of research conducted, there are still limitations for capturing the ripple effect of particular outcomes and consequently much of this impact will remain unknown. In addition, finding methods to capture change that occurs over time and as a direct result of the service's work is extremely difficult.

# 6. Outcomes at the level of services: organisational or process outcomes regarding good practice

The literature consistently supports a range of 'best practice' approaches or processes of working within the community mental health sector that are intermeshed with quality. These approaches include:

- 1. Recovery oriented practice;
- 2. Strengths based approach;
- 3. Person centred approach;
- 4. Human rights approach;
- 5. Social determinants of mental health perspective;
- 6. Family centred approach (predominantly in children's services).

These methods are complementary, and in general, respectful of the individual and their family or carer. Each of these practice approaches is summarised briefly in Appendix 2. Each approach includes literature identifying the expected elements of good practice and usually some methods for measuring these. In some instances, research has also evidenced a causal link between the elements of best practice and outcomes for service recipients. In this way, in some studies, documenting the presence and extent of elements of good practice has become a proxy indicator for outcomes for consumers. That is, though outcomes of consumers are not directly measured or evidenced, they can be assumed given the elements of good practice that are known to lead to these are evidenced to be present. However, caution should be used when adopting this approach to outcome measurement as the causal link between elements of practice and outcomes for consumers is sometimes weak or not yet established.

# Service quality measures/performance standards

Sitting within the aforementioned suite of approaches, Western Australian, interstate, national and international literature documenting good practice indicators or standards was analysed. The following cross-cutting domains of quality practice emerged from the analysis:

<u>Choice and control</u>: the service supports choice, ensuring that individuals determine their journey of recovery.

Inclusive of all:

the service supports individuals and their respective families/carers from diverse backgrounds, paying particular attention to gender, age, disability, cultural and linguistic background, sexual orientation etcetera.

Flexibility: the service is flexible in its structure to adequately support individuals and their

family/carer with their diverse aspirations and requirements.

<u>Participation</u>: the service's support structures have enabled individuals and their family/carer to

participate in their community across a range of life areas of their choosing. The service

ensures individuals are also provided with opportunities to participate in service and

program design and evaluation.

Accountability: the service is accountable to the individuals they support. Feedback from individuals

and their family/carer feeds directly into the service structural mechanisms to facilitate

and uphold best practice.

Working together: the service works with individuals, their families and carers, along with community and

government groups, organisations and services, ensuring the individual is supported in a

holistic manner.

(Citizens for Mental Health, 2004; O'Brien, 1989; MHS, 2010; HM Government 2011; DHSV, 2011; NIHCP,

n.d.; NMAHS MH, 2011; Commonwealth of Australia, 2009; Commonwealth of Australia, 2010) .

The relationship between individuals, their carer/family and community is also mentioned in service standards. Standards involve overcoming barriers that individuals with mental health or illness experience such as stigma and prejudice. They also include a social determinants approach —looking at and addressing the broader influences that play a role in contributing to mental health and illness such as poverty and housing (Citizens for Mental Health, 2004; MHS, 2010).

# Indicators of quality service

The literature documenting standards or service indicators for community mental health services is limited. However, in *A guide to person-centred excellence. Application for services for people with mental illness and people with substance use-disorder, the* Council on Quality and Leadership (2010) provides a comprehensive set of thirty four 'success' indicators across eight service components that include:

- 'Person-centred Assessment and Discovery
- Person-centred Planning
- Supports and services
- Community Connection
- Workforce
- Governance
- Quality and Accountability

• Emerging Practices in Individual Budgets' (CQL, 2010).

Guiding questions, rather than a measurement tool as such, are included under each indicator to support services to consider how they can strive to meet the indicator. For example, the indicators related to 'Supports and Services' include: people have authority to direct supports and services; supports are flexible; support options are accessible; people manage supports and providers; etc (CQL, 2010: 6).

In addition, the Council on Quality and Leadership (CQL) have developed resources for services that are person centred in their delivery and approach. Resources include the development of Personal Outcome Measures (POMS) that can be tied in to measure service quality as well as outcomes, as opposed to 'compliance with organisational processes' (CQL 1999:14, 1999a and n.d.). CQL's quality and outcomes approach to service delivery is consistent with Western Australia's human service sector's transition from block funding to individualised funding. Service outcomes are directly connected with how effective individuals and their families or carers assess the service is in terms of meeting their individual outcomes.

In Western Australia, the Mental Health Commission is currently preparing the Community Mental Health Service Sector to adhere to the Commonwealth of Australia's National Standards for Mental Health (Mental Health Commission, 2010; Commonwealth of Australia, 2010). Current Australian and international standards and performance indicators centre around flexibility, individualised and accountable services that promote choice, inclusion and participation.

A range of approaches and data collection instruments relevant to measuring service quality are listed in Appendix 3. This is not a comprehensive list.

#### 7. Developing systems to measure outcomes in human services

Once outcomes are agreed upon, and concepts defined, much of the work of outcomes measurement falls to service agencies. In many instances (for example, see the disability sector in Victoria), though outcomes are identified and defined by the government, the processes for collecting and analysing data, and for organising these systems of monitoring and research falls to individual agencies. This next section highlights some of the key areas to be considered by agencies when developing outcomes measurement systems and methods.

# Criteria for selecting or developing data collection instruments

Some work has been conducted to guide organisations in their selection and development of data collection tools in relation to outcomes measurement. Andresen (2000) reviews a range of outcome measurement

tools frequently used in rehabilitation and disability research, and identifies a set of eleven 'desirable characteristics' of such tools. In addition, Quilliam and Wilson (2011) report a further set of characteristics identified through consultation with service providers within a large Victorian disability organisation. Both the Andresen (2000) and Quilliam and Wilson (2011) criteria are discussed in detail in Quilliam and Wilson (2011), and are summarised briefly below:

## Concept capture

Does the data collection tool measure the outcome areas required? In particular, Quilliam and Wilson (2011) report that additional considerations here may be considerations of allowing a breadth of outcomes or narrowing the outcome set to be measured, as well as consideration given to the importance of self-reported and defined outcomes by the consumer.

#### Norms, standards and values

Andresen (2000) and Horsch (2005) both identify the importance of considering whether the data collected is comparable to other data sets (for example, to previous cohorts of consumers or benchmark data, or the general population, or other service recipients).

#### Measurement model

Does the tool capture the full range of differences among respondents?

# Item/ instrument bias

Does the tool capture results equally effectively/ accurately for people of different cultures, social circumstances, health status, impairments etc?

#### Respondent burden

Is the length, format, and content acceptable to respondents? In particular, Quilliam and Wilson (2011) document a priority for the tool to enable self-report by consumers, and to be brief and easy to use.

#### Administrative burden

Is the tool 'short, scored easily, without the need for a sophisticated program, and ... [does] not require a highly trained and specialized interviewer or rating expert' (Andresen, 2000, p. S18). Quilliam and Wilson (2011) also identified the need for the tool to be embedded into service delivery practice and administration supported by service delivery staff.

# Reliability and Validity

Does the tool give a consistent answer when no real change has occurred? Does the tool accurately measure what it aims to measure? Quilliam and Wilson (2011) noted that this was a contentious issue within their context. One strategy adopted in this context was to enable multiple respondents to report on the tool, i.e. service provider viewpoint, carer viewpoint, and consumer viewpoint.

# Responsiveness

Can the tool capture change that is meaningful to individuals? Is it sufficiently sensitive to capture small changes expected? Is it administered within timeframes within which changes could reasonably have been expected to occur?

# • Alternate/accessible formats

Is the tool available in a way that is accessible or most appropriate to the respondent? This might include via interview, written format, assisted self report, Braille, computer-based, with visual prompts etc.

# Culture/language adaptations

Are their versions of the tool for sub groups, eg different cultures, etc? Andresen (2000) notes that ideally, the tool has been developed with input from a range of different sub groups. In general, it is important to recognise that an outcome measurement tool may not be a 'one size fits all'. It is important to consider whether a tool is more suited to a certain cultural group than another.

# Approaches to measuring individualised outcomes

An ongoing tension exists in the measurement of outcomes in human services, between a focus on measuring individualised outcomes and a focus on outcomes that reflect group or population trends of the consumer group.

Individualised outcomes measurement reflects a strong practice model in many human services, including mental health, that focuses on personalised or individualised services oriented around supporting the consumer's self identified goals or areas of life change/achievement. As a result, services — and sometimes funding (for example, through individualised funding or personal budgets) — are becoming highly individualised in nature, and work to meet a wide range of goals identified by their many clients. This poses particular challenges for outcomes measurement within services. In this context, outcomes measurement is therefore targeted to measuring the extent to which individuals achieved their goals or desired changes. Outcomes data for consumers may not be able to be easily aggregated within the service to reflect levels of overall outcomes achievement.

A range of models are operational in this space, the dominant ones being Person Centred Planning / Review, and Goal Attainment Scales. Some others are discussed by Quilliam and Wilson (2011) including The Most Significant Change Tool (Davies and Dart, 2005) which is used largely in development work in overseas aid contexts.

Person Centred Planning (PCP) literature provides multiple formats for developing and laying out person centred plans, including the identification of desired goals or actions. Despite the resources available to support the planning process, there are few resources available to support the documentation of outcomes resulting from service delivery following planning. Service agencies are largely developing their own internal processes for capturing outcome information within PCP approaches, mostly as part of Person Centred Reviews. Several examples exist of this approach including Halton Borough Council (2010) Person Centred Outcome Focused Review. Document for Care Managers, which includes a format for documenting outcomes, along with what worked and did not work in relation to achieving these. Similarly, Wilson & Campain (2008) discuss an Individualised Client Plan Review, covering similar terrain and include a discussion of the complexities of developing a data collection tool for individualised outcomes. Individualised planning also occurs typically in the Early Childhood Intervention Sector via the use of variously named Family Service and Support Plans. One example of attempting to use these Plans to measure outcomes achieved against stated goals is found in Wilson & Campain (2011). These authors also provide a critique of this method of rating goal achievement, identifying some concerns in regard to its use including the difficulties of measurement where goals identified are longer term and not likely to demonstrate change within service delivery timeframes.

A common tool used to assess the achievement of individuals goals is the Goal Attainment Scale (GAS) developed by Kiresuk & Sherman (1968). Originally developed for community mental health contexts, it has had wide application in a range of contexts including rehabilitation, allied health, community development and disability. As with other person centred planning approaches, the GAS allows the user to identify their own goals and a matrix is then used to identify levels of possible goal attainment, matched to a score ranging from –2 to +2 (Smith, 1994; Cardillo & Choate, 1994). The advantages of GAS appear to be that consumers can participate in goal setting and rating matched to their own unique aspirations. The disadvantages relate to the constraints of pre-determining outcome indicators prior to service delivery (as outcomes may later manifest in unexpected ways) (Quilliam and Wilson, 2011). Though utilising a quantitative scale, the GAS data is not comparable across individuals and therefore cannot be easily aggregated into service or consumer group data. A full review of the GAS and its use in community based mental health is beyond the scope of this paper.

Drawing on the above work, Quilliam and Wilson (2011) report on the development of the Measurement of Outcomes of Services and Supports (MOSS) tool. The tool is based on a person centred planning process and provides a pre and post service data collection process in regard to an identified goal. The tool (Hagiliassis et al, 2011) is available for public use and Quilliam et al (2010) provide some useful comments in regard to its utility, accessibility and reliability following two trials of the tool in a disability service.

# Challenges of establishing and maintaining an outcomes measurement approach in the human services

There is a body of research that discusses the factors affecting the development and operation of effective outcome measurement systems within service provider organizations. A full review of this literature is beyond the scope of this paper. A short summary of key issues is provided below.

# Costs

The resources required to establish research, monitoring and evaluation functions within human service organizations are significant. United Way, an organization of 1300 autonomous local agencies in the USA, estimates that it has spent \$2.4M on accountability systems including outcomes measurement between 1995-2000 (note, the organisation's gross annual income is in the order of \$4 billion). By 2008, it estimated that around 450 local agencies (of the 1300) were implementing outcome measurement (that is, participation of around one third of its total agencies) (Hendricks, Plantz & Pritchard, 2008).

# **Timeframes**

Anecdotal evidence suggests that considerable time is required to establish outcomes measurement systems. United Way identifies a long lead team in the development to implementation of an outcomes measurement approach, taking between two and four years from identification of outcomes through to getting meaningful results from data. They argue that public acknowledgement of this timeframe takes the pressure off to generate results immediately. Additionally, they argue that despite the extended timeframe, an effective system identifies clear actions and progress along the timeline to ensure progress is steady and key tasks are undertaken when required (Hendricks, Plantz & Pritchard, 2008).

# Focus on program improvements not compliance with external requirements

While outcome measurement receives much attention, less attention is paid to how to make this data useful for service delivery. Disability practitioners (2001) argue:

The point is not to collect information - it is to learn enough about how things are going so we can keep going or change direction with confidence. We want monitoring which leads to action to improve ... [practice], and to have a positive impact on people's lives (Ritchie et al, 2001: 177).

United Way argues that adopting the rationale of program improvement rather than compliance with external standards and targets is an important motivator for service participation in and use of outcome measurement (Hendricks, Plantz & Pritchard, 2008). Consistent with this approach, Quilliam & Wilson (2011) report that practitioners in their service context required a focus on collecting data in relation to the factors that enabled and hindered outcome achievement, as this data was considered critical to service improvement.

# Staff skills and resources

Much has been written about the need to train staff in areas related to outcomes measurement. United Way found that their service agency staff did not have the skills necessary to implement an outcomes measurement approach. Nor are these skills easily or quickly acquired. As stated by the authors, while they fully acknowledge the other skills of staff, 'it is simply not easy for ... staff to become skilled practitioners of outcome measurement' (Hendricks, Plantz & Pritchard, 2008:21). United Way found that both staff training as well as ongoing 'content-specific' technical assistance was required to support staff. Compounding the problems of staff training was a relatively high staff turnover rate so that, in some agencies, around one third of those trained had left their jobs by the following year (Hendricks, Plantz & Pritchard, 2008).

Additionally, United Way found that emphasis was required on resourcing both the 'front end', i.e. the development and administration of data collection processes, as well as the 'back end', i.e. the analysis, interpretation and use of data to effect service improvements. United Way had paid insufficient attention to the 'back end' of the process and found this difficult as traditional skills and training in evaluation and research focus on the front end (Hendricks, Plantz & Pritchard, 2008).

UWA utilized a significant set of resources including a Manual, training kits (including videos), guides to computer software, etc. In addition, United Way implemented a train-the-trainer strategy which included a four and a half day training component for trainers, however, the authors contend that this strategy had unrealistic expectations about the level of expertise trainees could acquire via this mode. Staff and services are further resourced by a team of six national senior evaluators (Hendricks, Plantz & Pritchard, 2008).

# Performance targets

United Way advises against the identification of performance targets for outcomes, until sufficient data has been collected over time to evidence what targets are actually achievable (Hendricks, Plantz & Pritchard, 2008).

## General versus localised measures and data collection processes

United Way took the approach that local agencies were best placed to identify the outcomes expected and to develop ways of collecting this data. However, they also acknowledge the value to linking services to national resources and compendiums of tools and approaches used by others (Hendricks, Plantz & Pritchard, 2008).

# 8. Conclusions – a way forward for outcomes measurement for community based mental health in Western Australia

There is evidence that the development and operation of an outcomes measurement process within human services is a complex and burdensome task. At the conceptual front end of the work, there is significant work in identifying and defining outcomes of most relevance. There are difficulties in developing data collection instruments that are congruent with consumer needs and experience, and have the support of service providers. Additionally, the data collection instrument needs to be accessible to a diverse range of consumers, relevant across cultures, easy to administer and analyse. Data collection itself is burdensome for consumers and service providers, and is therefore sometimes unreliable and/or incomplete. It is best when integrated into practice and becomes a part of routine service delivery (for example, initial goal setting and post service assessment and feedback). Data collection in the field of outcomes is a medium to long term commitment, as outcomes need to be understood as manifesting in both the short term, though are more likely to require a long term timeframe before they are evident. There is evidence that service providers frequently don't have the resource capacity or specific skill set for data analysis. Outcomes measurement has most value when it not only establishes the level of outcomes achieved, but provides data that points the way for service improvement and change. This requires questions that go beyond assessing the nature and extent of outcomes.

Such complexities suggest that the development of an outcomes measurement system for community based mental health services needs to be staged and pragmatic. In the first instance, of the three outcomes focuses discussed in this paper (outcomes for individuals, outcomes for communities, service quality outcomes), the sector should commence with work on outcomes for individuals and service quality outcomes.

In regard to outcomes for individuals, the 4<sup>th</sup> National Mental Health Plan identifies the outcome area of social inclusion. There is already a significant body of work in this field, though it appears that the existing mental health bodies (including the AMHOCN) have not engaged with it. It is recommended that the sector engage with the domain areas of social inclusion and prioritise the top three or four of these (eg. employment, social relationships, etc), in the first instance. Outcome data collection items could then be developed or adopted to capture data about each. Further domains of importance could be added as the outcome work progresses. In addition, given the importance of individualised and person centred service delivery, a method for capturing outcomes related to the consumer's self identified goals should be developed for services to utilise if appropriate. Work by Quilliam and Wilson (2011) might provide a useful guide here.

In regard to outcomes related to service quality and process, this is likely to be work led by the primary funder, in this case, the WA Mental Health Commission. In the first instance, the sector could engage with the list of quality domains listed in section 6 of this document, agree on or prioritise these, and note any concerns regarding their appropriateness, or the need for their re-definition, in remote, rural and cross cultural service delivery areas.

# Appendix 1: Further studies in mental health that include a secondary focus on social inclusion

Carlson Et Al, (2011) conducted a study of 609 adults receiving psychological treatment services in the United States to validate social health scales that assess mental health outcomes. The study reports on several of these that include a focus on social inclusion related items. The California Quality of Life (CA-QOL) is a 40-item survey developed to assess patient reported outcomes. It incorporates objective life conditions (covering family contacts, social contacts, finances and arrests) and subjective satisfaction with life conditions (covering satisfaction with life, living situation, family relations, social relations, daily activities, leisure activities, safety, and health). Reliability was assessed as high. The Social Functioning Questionnaire (SFQ) is an 8-item instrument measuring an individual's perception of functioning. The items include assessing the successful completion of and stress related to tasks at work and home; money problems; difficulties in getting and keeping close relationships; problems in sex life; relations with family and other relatives; feelings of loneliness and isolation; and enjoyment of spare time. Reliability and construct validity has been shown to be good (Carlson et al, 2011).

Test et al's (2005) study in the United States examined the construct validity and utility of a self-report 18item Satisfaction with Life Scale which measures satisfaction in four domains: living situation, social relationships, work, and self and present life. The authors conclude that the tool is easily completed (individuals complete it during assessments and may be assisted to complete) and they support its construct validity finding it a useful tool for assessing subjective satisfaction with life. However, they suggest more study to determine the tool's ability to detect predicted changes across time (Test et al, 2005).

In the Netherlands, a study by Alfonso et al (1996) analysed the Extended Satisfaction with Life Scale (ESWLS) - a 50-item self-report scale that measure satisfaction with life in nine domains: general life, social life, sex life, relationship, self, physical appearance, family life, school life, job satisfaction. The scale was completed by 302 individuals and the authors conclude that it is a reliable instrument that may be used to monitor change throughout an intervention (Alfonso et al, 1996).

# Appendix 2: Summary of main practice approaches in community based mental health

### **Recovery oriented practice**

Working within a recovery model requires community mental health services to support individuals with their 'self-defined personal recovery' (DHSV, 2011). This involves supporting individuals to be and live in ways that are meaningful to them. Supporting individuals with their self-determined journey of recovery involves valuing and facilitating notions such as 'self-management, personal growth, empowerment, choice and meaningful social engagement' (DHSV, 2011:2).

## Strengths based approach

Strengths based approaches are used intermittently across the human service sector and West Australia's Disability Service Commission has a strong background in strengths based practice. This approach ensures that service providers plan and work together with the individual, jointly identifying strengths and building opportunities from strengths. It is derived from the premise that every individual has the capacity for growth and they are experts in their own lives. The strengths based approach has been shown to positively contribute to individuals' well being and quality of life (Rangan Aarti, S., 2006).

## Person centred approach

Person-centred approaches can be characterised by:

- consideration of the aspirations and capacities of the individual rather than needs and deficiencies;
- inclusion of the individual's family and social networks;
- emphasis on providing support to achieve goals, rather than limiting those goals to what a service can typically provide (Mansell & Beadle-Brown 2004).

The person centred approach is strengths based in nature, and relies on getting to know the individual. Respecting and understanding where the individual is at and what is important to them will lead the way in terms of identifying how and in what form the person will be supported to live a life that is meaningful to them.

# **Human rights approach**

Keeping in line with various UN Conventions on human rights, a human rights approach is taken when supporting and including people with a mental health problem or mental illness. Any activities and outcomes that are facilitated by involvement with the community mental health sector will uphold and further enhance the rights of people with mental health problems or a mental illness as active citizens.

#### Social determinants of health approach

The social determinants approach recognises the links between poverty and disadvantage with mental health (Citizens for Mental Health, 2004; VHPF, 2005; Sampson et al 2010). Community Mental Health Services play various roles in relation to support and advocacy to interrupt the cycle of poverty, tackle barriers and open up greater opportunities for individuals and their families/carers.

# Family centred approach

Family centred practice is a key concept in early childhood intervention and children's services. There are many definitions of family centred approaches and family centred services. This set of practices is relevant across a range of service areas including early childhood care, education settings, services for families with children with special needs, child protection, family policy, health and hospital settings. Viscardis (1998) defined a family-centred approach as one that:

... begins with the child's and family's strengths, needs and hopes, and results in a service plan which responds to the needs of the whole family. It involves education, support, direct services and self-help approaches. The role of the service provider is to support, encourage, and enhance the competence of parents in their role as caregivers (p. 44).

# Appendix 3: Methods to assess service quality

Title of Standards or frameworks	Country/ state	Name of service or institution/ Author	Tools	Other methods/Notes
Quality Standards Programme	UK	National Institute for Health and Clinical Excellence	<ol> <li>NHS mental health community survey.         <u>www.cqc.org.uk</u> </li> <li>NHS staff survey. <u>www.cqc.org.uk</u></li> </ol>	Some quality standards had no methods available for measurement. For example, Draft Quality Statement 22: <i>Combating Stigma</i> has no methods or existing indicators identified
What's Worth Working For? Leadership for Better Quality Human Services	USA	John O'Brien		A set of guiding statements rather than measurement indicators are included according to each service accomplishment.
Healthy Minds, Healthy People,	British Columbia, Canada	Ministry of Health Services, Ministry of Children and Family Development		Internally developed method to collect and analyse data from key performance indicators across governments and systems
No health without mental health	UK	HM Government	Broad population outcome indicators are measured by statistical increases/decreases.	

Framework for recovery-oriented practice	VIC, AUS	Department of Health		Guiding principles, capabilities, practice and leadership points for each domain.
Fourth National	AUS	Commonwealth of	Several tools are recommended within the	The majority of these provide demographic, population
Mental Health		Australia	plan such as:	data not service quality data
Plan			-National Survey of Mental Health and	
			Wellbeing,	
			-Survey of Disability, Ageing and Carers,	
			-Household, Income and Labour Dynamics in	
			Australia (HILDA)	
			-Adaption of Jorm's mental health literacy	
			survey (1997)	
			-National Minimum Data Sets	
			-Activity Participation Questionnaire	
			(developed in NSW)	
			-National MindMatters and KidsMatter	
			initiatives	
			-Number of mental health care plans	
			developed through General Practitioners	
			-National Drug Strategy Household Survey	
			-Australian Bureau of Statistics	

			<ul><li>-2007 National Survey of Mental Health and Wellbeing</li><li>-Community Mental Health Care National Minimum Data Sets</li></ul>	
National Standards for Mental Health Services	AUS	Commonwealth of Australia		Set criteria for meeting each of the 10 standards.  Services will be assessed against each criteria across all standards except for the consumer standard
Standards for Psychiatric Disability Rehabilitation and Support Services	VIC, AUS	Department of Human Services		Guiding practice principles and rights.

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