Literature Review Outcomes Measurement in Disability Services:

A review of policy contexts, measurement approaches and selected measurement tools

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FOR PEOPLE WITH A DISABILITY

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INTRODUCTION

There is increasing interest in determining the outcomes of services and supports in the human services sector. This paper introduces a recently developed outcomes measurement instrument designed for use in disability services and supports, and reviews existing instruments of similar purpose where there is published literature. This review aims to position the new instrument, the Measurement of Services and Supports (MOSS) tool, in relation to: definitions relating to outcomes measurement; current policy contexts relating to measuring outcomes of services provided to people with disabilities; and existing instruments, paying particular attention to a set of criteria the MOSS tool was designed to meet. The review will provide a useful summary of measurement instruments, identifying their respective intentions, strengths and limitations.

DEFINING OUTCOMES

There is now a growing body of literature about the process of measuring outcomes of human services. This literature focuses attention on the definition of outcomes in a range of ways, both as distinct from definitions of 'outputs' and 'processes' related to achieving outcomes, and in terms of the conceptual delineation of outcomes relevant to particular groups. The interest on 'outcomes' focuses attention on the change that occurs for people in a given population (or a community as a whole), as a result of interventions delivered. The Steering Committee for the Review of Government Service Provision delineates between outcomes and outputs as follows:

Outputs: "the service provided by a service area"

Outcomes: "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).

According to the Australian Bureau of Statistics, 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 'family' or 'self esteem' is important, how do we define 'family' or 'self esteem'?);

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, 2003, ch 1).

Each of these elements is open to debate and a wide range of viewpoints. Stakeholders commonly disagree on what is important and what is to be measured, as well as what phenomena are the most useful or valid indicators of this. In simple terms, an indicator is understood as a key "measure of something that matters" (Wiseman et al, 2005). Indicators can measure inputs, process, outputs, and/or outcomes. An overview of each of these follows:

Input indicators: measure resources (human and financial) related to a particular program or intervention (e.g., number of planners). Input indicators can also include measures of characteristics of target populations (i.e., number of clients eligible for a program).

Process indicators: measure ways in which program services and goods are provided.

Output indicators: measure the goods and services produced (quantity, efficiency: e.g., number of people served, speed of response to complaints). These indicators can be identified for programs, sub-programs or organisations.

Outcome indicators: measure the broader results achieved through the provision of goods and services. These indicators can exist at various levels: population, agency, and program (Horsch, 2005).

Friedman (1995) argues that measures of service achievement or results need to combine a focus on outputs, process and outcomes in order to capture the complex interaction between quantity and quality, effort and effect.

The Harvard Family Research Project suggests the following criteria may guide the selection of indicators:

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

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

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 (Horsch, 2005)?

Most importantly, however outcomes are defined and indicators selected, Ritchie et al (2001) argue that such investigation is critical to evaluating performance and generating information to guide future action. Measuring outcomes enables comparison across organisations, populations or programs and interventions. Such information informs decisions about future actions and is a strong basis for communicating with an organisation's constituency about the efficacy of its actions and reasons for decisions about resource allocation. Ritchie et al (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 improved… [practice], and to have a positive impact on people's lives" (Ritchie et al, 2001: p.177).

This suggests that any outcomes measurement approach must also ensure that it can identify the type and extent of outcomes as a result of a service intervention, but also the factors that enhance or impede these.

MEASURING OUTCOMES IN THE DISABILITY SECTOR – the policy context

There are several significant policy environments which influence work to develop outcome measures relevant to people with disabilities in Australia: 1) the international policy environment; 2) the Australian Commonwealth Government policy environment; and 3) the Victorian State Government policy environment.

The international environment is becoming increasingly influential in the arena of outcome measurement in regard to people with disabilities. A significant new development in the policy and legislative arena is the most recent United Nations (UN) Convention on the Rights of Persons with Disabilities, which was endorsed by the United Nations National General Assembly on the 13th of December 2006 and entered into international force on the 3rd of May 2008. This Convention endorses the active participation of all people with disabilities in all areas of community and economic life (UN, 2006). It identifies eight general principles and fifty articles identifying minimum rights of people with disabilities. The principles articulate concepts such as equality, autonomy, independence, opportunity, accessibility, identity, participation and inclusion (UN, 2006).

As a signatory to the Convention, the Australian Commonwealth government needs to evidence compliance with its principles and articles. Previously, the Commonwealth government articulated its funding and policy directions through the Commonwealth State Disability Agreement (CSTDA). This Agreement specified five national strategic policy directions along with performance monitoring and reporting requirements. A core objective of the CSTDA was for governments in Australia to:

…strive to enhance the quality of life experienced by people with disabilities through assisting them to live as valued and participating members of the community (Commonwealth of Australia, 2005).

The CSTDA is currently being replaced by a new National Disability Strategy currently being drafted (2010) by the Commonwealth government. Though not yet finalised, published documents already identify that the Strategy will be aligned with the principles of the United Nations Convention on the Rights of Persons with Disabilities (Commonwealth of Australia, 2008). The Commonwealth Government's 2008 Discussion Paper on the National Disability Strategy suggests the following outcome areas:

People with disability and their carers have an enhanced quality of life and participate as valued members of society. Core outcome areas are:

* People with disability achieve economic participation and social inclusion;

* People with disability enjoy choice, wellbeing and the opportunity to live as independently as possible;

* Families and carers are well supported (Commonwealth of Australia, 2008).

Despite a continuity of emphasis on the outcome areas of participation and quality of life, to date, governments have proven ineffective in developing measurement frameworks to capture outcomes in these areas. In 2005, the Audit Report of the Auditor General (Commonwealth of Australia, 2005) identified a significant shortfall in regard to measuring outcomes specified in the CSTDA. The Report identified that as yet "no indicators of the quality of life of people with disabilities, their participation in the community, their value in community, or any related parameters" are included in the performance framework of the CSTDA (pg. 42). Development in this area was part of Recommendation 1 of the Report. This echoed concerns raised by the Steering Committee for the Review of Government Service Provision in its 2004 report, which identified that no State/Territory had effective measurement indicators or methods to assess quality of life, wellbeing or social participation of people with disability. As a result, in its recent Discussion Paper, the Commonwealth Government (2008) suggests that a "more developed research agenda" is needed and that a future reporting framework will be established to "align… the United Nations Convention on the Rights of Persons with Disabilities and the National Disability Agreement" (p.10).

Within Victoria, the Victorian State Disability Plan (2002-2012) provides the policy framework in relation to people with a disability (Department of Human Services (DHS) 2002). The Plan has three over-arching goals that focus on: enabling people with disabilities to pursue 'individual lifestyles'; the building of 'inclusive communities'; and the provision of leadership in these change areas (DHS, 2002: p.11). In this context, the Department of Human Services has produced a Quality Framework for Disability Services. This framework identifies 'outcome standards' and 'life areas'. The Outcomes Standards for Disability Services (DHS, 2007) prompt disability services to:

"…consider the influence and impact service has upon political, cultural, health and well-being, economic and social outcomes for people with a disability" (DHS, 2007: p.1).

Five outcome standards are identified:

Individuality

Each individual has goals, wants, aspirations and support needs and makes decisions and choices about their life.

Capacity

Each individual has the ability and potential to achieve a valued role in the community.

Participation

Each individual is able to access and participate in their community.

Citizenship

Each individual has rights and responsibilities as a member of the community.

Leadership

Each individual informs the way that supports are provided (DHS, 2007: p.2).

Attendant to the five outcome standards is a set of sixteen (16) life domains that reflect "the things that are important to people with a disability and their family members and carers" (DHS, n.d: p.1). Identified life areas are:

- always learning
- being part of community
- being independent
- being safe
- building relationships
- choosing supports
- communicating

- doing valued work
- exercising rights and responsibilities
- expressing culture
- having fun
- how to live
- looking after self
- moving around
- paying for things
- where to live (DHS, n.d.: p.12-13).

These are further expanded to generate a set of 'evidence indicators' for each outcome standard, comprising between seventeen (17) to twenty-eight (28) evidence indicators per standard that outline a mix of outcome, satisfaction and process measures, and as such confuse the conceptualisation of 'outcome' measurement.

This review of the policy environment suggests some common and competing thrusts in outcomes definition in relation to measuring the impacts of services and supports for people with disabilities. In common across the three environments is a focus on concepts relating to 'inclusion', 'participation', autonomy' and 'independence'. In particular, the international environment, via the UN Convention (UN, 2006), has broadened notions of inclusion and participation to span domains across the whole of life, including social, economic, cultural, spiritual, educational, political, recreational, public and personal arenas. It appears that the Australian Commonwealth government will reinforce these notions within the National Disability Strategy. By contrast, the details of the 'life areas' and 'outcome

standards' of the Victorian government represent a translation of some of these concepts into a more simplified form. The Victorian outcome standards do not appear to explicitly seek to measure outcomes across the range required by the UN Convention (2006). It is as yet unclear the extent to which governments and services will be required to evidence outcomes against this fuller conceptualising of inclusion, equality and participation.

THE DEVELOPMENT OF THE MOSS TOOL

In 2005, Scope, a major Victorian disability service provider, commenced an extended research project to develop an outcomes measurement framework and data collection and analysis instruments related to it. In five years, this work has progressed significantly and includes an outcomes measurement framework (a first iteration published in Wilson, 2006), and six data collection instruments developed and trialed. Of these, the Measurement of Services and Supports (MOSS) tool was the first.

Work on the MOSS tool commenced prior to 2005 with the convening of a working group comprised of therapists and psychologists involved in the delivery of these 'specialist' services to people with disabilities in Scope. The group's task was to develop a way to measure outcomes of these services for people receiving them. Around this time, 'specialist services' units in Scope had also participated in research to measure the extent of their family centred practice in therapy and psychology service delivery to children and their families (Scope, 2004). Essentially this represented a focus on process indicators (as aligned with the domains of family centred practice) rather than outcomes of these services. This work focused attention on the need to identify outcomes of services, and for the need to generate information about the impact of services on adults with disabilities (since some data had already been generated about families and children).

The context for the development of the MOSS tool was influential and can be summarised here as follows. Scope's specialist services were understood to include occupational-, physio- and speech-therapy as well as psychology services, with staff working in regional teams supported by Statewide discipline-specific advice and resource support. Regional teams evidenced varying degrees of collaboration and inter-disciplinary work. This collaborative approach was reinforced by the prevailing practice approach of client-centred or person-centred work which was experiencing an increasing focus. Alongside this thrust, was an increasing emphasis on supporting individuals with disabilities to achieve broader life goals (such as going dancing, maintaining employment etc), rather than a more narrow focus on more short term and often functionally described goals (such as increasing muscle dexterity in one limb). Predominately, specialist service staff worked with clients to set individual goals and to plan services and supports to enable these. For some staff, this led to increasing roles in community capacity building activities as well as individual work with clients. These developments led to much discussion about the nature of 'therapy' and 'psychology' and its link to wider social change in clients' environments.

In terms of outcomes measurement this led to discussion around the need to enable a broad range of outcomes to be defined by people with disabilities (within their goal setting process), and a measurement method that captured diverse changes. Additionally, because staff working directly with clients, worked collaboratively with other specialist service staff as well as others in the client's environment, it was felt that ideally an outcomes measurement tool would capture the total effect of this collaborative work, rather than atomise its components back to the focus of particular discipline areas (eg OT, physio etc). Due to a significant portion of specialist service now being focused on community capacity building, a tool that captured outcomes as a result of this work was also felt to be relevant.

As a result of lengthy discussion, the working group identified a range of criteria that an outcomes measurement instrument would need to meet in order to be useful and appropriate to specialist services work. These are detailed in the next section.

The working group engaged in an initial literature review to identify potential tools fitting this criteria. No tools were found to be suitable in this review. As a result, the team developed its own tool drawing on ideas from a range of sources and from practitioners. In 2006, the MOSS tool was trialed in two regional specialist services teams. Data collected including information about the utility of the tool and included focus groups with staff who had trialed the tool. Consequently, the tool was further revised and improved. A second edition of the tool, also comprising in-built diagramatic rating scales, was adopted for use in 2009 by all regional teams with adults with a disability receiving therapy or psychology services in Scope. The MOSS tool has also been used in other service settings both within and beyond Scope. Results of the trial and further use of the tool, including initial validation data, have been widely presented at Australian disability and therapy conferences.

PARAMETERS FOR OUTCOMES MEASUREMENT DESIGN FOR THE MOSS TOOL

Andresen (2000), in her introduction to the review of a range of outcome measurement tools frequently used in rehabilitation and disability research, identifies a set of eleven 'desirable characteristics' of such tools. These form a useful way to organise the presentation of the requirements identified for the use or development of an outcomes measurement tool in the specialist services context in Scope. As is discussed below, a number of additional criteria were identified by the Scope working group, that have not been identified by Andresen (2000).

Concept capture

Andresen's first criterion is that of 'conceptual' referring to the need for outcome domains or central concepts to be captured by the tool. This aligns with both the ABS (2003) explanation of outcomes measurement, and Horsch's (2005) identification of adequate 'focus'.

In this regard, the Scope working group required a tool that would:

- focus on outcomes, rather than outputs or processes;

- enable a broad range of outcome types to be named and measured. These include outcomes generated as a result of service provision from different services and across professional disciplines (at least including psychology, physio-, occupational- and speech-therapy), as well as a wide range of outcome types and levels across life domains (beyond diagnosis or clinical outcomes);

- measure person-defined outcomes (ie those identified by persons with a disability). Here, the tool also needed a compatibility with goal oriented / defined interventions.

In addition, the Scope working group wanted to capture several measures around a person's view on outcomes including their evaluation of their performance level in regard to the goal/outcome (pre- and post-service) and their satisfaction with this level. To meet this, the tool needed to:

- use indices of measurement that enable the person with a disability to rate the level of their performance and their satisfaction with this, in relation to nominated goals or outcomes (pre and post service).

Measurement model

Andresen (2000) suggests that tools need the capacity to capture detail and breadth of responses.

The Scope working group desired a tool that was:

- able to capture participation outcomes as well changes to the environment that facilitated these.

Responsiveness

Sensitivity to change and the level of client-centredness is valued within this criterion (Andresen, 2000).

This was also an important consideration for the Scope working group, that required a tool that was:

- sensitive to small changes for individuals.

Respondent burden

This criterion assesses the match of the tool with the capacity of the respondent to complete it. Andresen (2000) also values the involvement of people with disability in the instrument design.

This was of particular concern to the Scope working group. In this regard, the working group required a tool that was:

- brief and easy to use (through design and implementation characteristics) for people with disabilities.

- based on self-report by people with disability, rather than proxy or 'expert' reporting, which would enable the subjective experience of the individual to be captured.

Alternate accessible forms

Given the focus on outcomes in the disability sector, Andresen (2000) identifies accessible and alternate formats of tools as important, along with testing of these to validate their appropriateness.

Likewise, the Scope working group prioritised this area, requiring a tool that was:

* accessible (with and without verbal support by practitioner) to people with a wide range of disabilities particularly including people with intellectual disabilities. However, it was recognised that development of a range of accessible formats may take many iterations of the tool, following initial testing and validation.

Administrative burden

Andresen (2000) recognises the importance of ease of data collection and analysis by researchers.

Similarly, the Scope working party required a tool that, whilst relying on the self report of people with disabilities:

* could be administered by Scope staff (therapy and psychology practitioners) within their existing time and workload allocations
* required low amounts of time allocation for data analysis.

Norms, standard values

Andresen (2000) highlighted the importance of the existence of comparative data, whether to a general population or other cohort, of benchmarking data for the same cohort.

While this was considered a bonus by the Scope working group, given the range of outcome areas likely to be reported, it was felt that comparable data was unlikely to be available. However, the working group did envisage repeat, periodic data collection through an outcomes measurement tool, so as to enable benchmarking of service performance.

Item/instrument bias; Reliability; Validity

The methodology used by Andresen (2000) is positivist in nature and therefore highly values a lack of 'bias' along with particular reliability and validity constructs.

The Scope working group was comprised of people with mixed views on methodology and indeed this remained a tension throughout even the trialing of the tool. Overall, the group felt that the views of people with disability participating in outcomes measurement were of paramount importance (suggesting a strong kinship with post positivist methodology). Additionally, given the nature of some impairments (eg cognitive), people's answers were likely to show a level of internal inconsistency. The working group also wanted to be

able to capture changing goals and outcome aspirations in recognition that individuals grow and change priorities across a period of service.

However, to mediate these issues of consistency and reliability, the working group valued the respective viewpoints of the person with a disability and others involved with the outcomes or service. This was seen to be a measure of triangulation around some areas of data collection. For this reason, the working group desired a tool that:

- clearly identified the respective perspectives of the person with a disability, the service provider/practitioner, others in the person's life, in relation to outcomes achieved and the factors influencing this.

Culture/ language adaptations

Andresen (2000) identifies the need for tools that are responsive to sub groups within the cohort. This was not an immediate consideration of the Scope working group at the time of development.

Factors affecting outcomes

In addition, to the above criteria, the Scope working group also identified several others, particularly pertaining to the critique by Ritchie et al (2001) that information is only useful to the extent it can improve service and direct the change focus. To this end, the working group required a tool that:

- identified barriers to outcomes
- identified enablers to outcomes.

In summary, the criterion for tool selection or development adopted by the Scope working group was as follows.

Table 1: Scope criterion for selecting or developing an outcomes measurement tool for use in specialist services contexts.

1. Focus on outcomes, rather than outputs or processes;

2. Enable a broad range of outcome types to be named and measured. These include outcomes generated as a result of service provision from different services and across professional disciplines (at least including psychology, physio-, occupational- and speech-therapy), as well as a wide range of outcome types and levels across life domains (beyond diagnosis or clinical outcomes);

3. Measure person-defined outcomes (ie those identified by persons with a disability). Here, the tool also needed a compatibility with goal oriented/defined interventions;

4. Use indices of measurement that enable the person with a disability to rate the level of their performance and their satisfaction with this, in relation to nominated goals or outcomes (pre- and post-service);

5. Be able to capture participation outcomes as well changes to the environment that facilitated these;

6. Be sensitive to small changes for individuals;

7. Be brief and easy to use (through design and implementation characteristics) for people with disabilities;

8. Based on self-report by people with disability, rather than proxy or 'expert' reporting, which would enable the subjective experience of the individual to be captured.

9. Be accessible (with and without verbal support by practitioner) to people with a wide range of disabilities particularly including people with intellectual disabilities;

10. Be able to be administered by Scope staff (therapy and psychology practitioners) within their existing time and workload allocations;

11. Require low amounts of time allocation for data analysis;

12. Clearly identify the respective perspectives of the person with a disability, the service provider/practitioner, others in the person's life, in relation to outcomes achieved and the factors influencing this;

13. Identify barriers to outcomes;

14. Identify enablers to outcomes.

ANALYSIS OF EXISTING OUTCOME MEASUREMENT TOOLS

Douglas et al (2005) argue that there are simply too many outcome measurement tools to review all that may be used within the disability field. As a result, this review will select a range of outcome measurement instruments that focus primarily on outcome rather than output or process measures and appear to be broadly consistent with the characteristics of the Scope specialist services environment. In this way, tools selected are designed to:

* measure outcomes of specific therapy services, such as physio-, occupational- and speech-therapy and psychology services;

* measure the life outcomes of adults with a disability in receipt of services and supports;

* measure the outcomes of services delivered via an explicit focus on goal setting and achievement.

In particular, tools selected are generally those that have been used within Scope for different purposes, or within other Victorian disability agencies.

Table 2: Published measurement tools analysed in literature review

Focus	Instrument	Authors and year of publications
Therapy and psychology services	Australian Therapy Outcome Measures (AusTOMs)	Perry, Morris, Unsworth, Duckett, Skeat, Dodd, Taylor & Reilly (2004)
	Canadian Occupational Performance Measure (COPM)	Law, Baptiste, Carswell, McColl, Polatajko & Pollock (1991; 1994; 1998; 2005)
	The Personal Wellbeing Index (PWI)	Cummins (1997), Cummins & Lau (2005)
Life outcomes of adults with disabilities receiving services and supports	Personal Outcome Measures (POMS)	The Council on Quality and Leadership in supports for People with Disabilities (1997; 2005)
	Functioning and Health Related Outcomes Model (FROM)	Australian Institute of Health and Welfare (2005)
Services delivered via goal setting	Goal Attainment Scale	Kiresuk & Sherman (1968), Kiresuk, Smith & Cardillo (1994)

In addition, a search for more qualitative methods, able to capture a wide and un-predetermined set of outcomes, uncovered the Most Significant Change tool, which is included in this review.

Each instrument is reviewed below. First a general description of the intention and scope of the tool is provided. Each tool is then analysed against the development criteria for the MOSS to determine its goodness of fit in relation to these.

MAJOR CONCEPTUAL TOOLS

There are many outcome measurement tools used within the disability field to measure the outcomes of service for people with disabilities. Many of these tools are based on the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organisation (WHO, 2001).

ICF

The ICF classification provides a "common language for describing health and health-related states" (WHO, 2001: p. 6) and as such has been used a basis for conceptualising experiences of disability, as well as the measurement of change in these 'states'. The ICF attempts to catalogue 'body functions', 'activities' - relating to the specific activity restriction as a result of the disability, 'participation' relating to the specific

participation restrictions associated with the disability, and 'environment' enumerating the range of environmental factors mediating the experience of disability. The ICF represents a major conceptual model in the disability sector and as such has underpinned categories of data collection and analysis in research, including the area of outcome measurement, as well as practice.

Whilst the ICF classification provides a useful framework, the literature highlights some critiques of this model, specifically in relation to the use of the four main concepts, in the identification of outcomes. One particular critique, is that the concepts often overlap in use, for example, the 'body functions' and 'activity' concepts overlap because of the natural relationship between a specific body function and a person's ability to complete a task or activity within an environment. Further, 'activity' and 'participation' concepts are often hard to distinguish from one another, due to the natural interrelationship between completing an 'activity' and 'participation' in a "fulfilling life role" (Noonan et al, 2009: p.1896). This suggests problems with concept capture (Andresen, 2000) or focus (Horsche, 2005), which are not unsurprising given the complexity of the concepts involved. Other limitations associated with using the ICF for outcome measurement include the lack of a subjective dimension (Noonan et al, 2009) and the placing of human function (body function, activity and participation) in a linear fashion, and thereby supporting the medical model, which places the problem with the individual with a disability and suggesting that the restrictions to participation are the result of the impairment (Van Campen & Iedema, 2007).

As many of the outcome measurement tools that are to be reviewed in this paper are based on the ICF's classification system, it is likely that some of the ICF critiques may be evident in these tools. Any such critiques will be noted within each discussion surrounding measurement tools.

TOOLS RELATED TO THERAPY AND PSYCHOLOGY SERVICES

Australian Therapy Outcome Measures (AusTOMs)

The Australian Therapy Outcome Measures (AusTOMs) is a collective name for three different outcome measurement tools, used in each of the Australian physiotherapy, speech therapy and occupational therapy professions (Perry et al, 2004). The AusTOMs were developed due to the need for a common or standard therapy outcome measurement tool within Australia (Unsworth, 2000) and were derived from the United Kingdom's Therapy Outcome Measures, or TOMs (Enderby & John, 1997). The domains used to rate outcomes are based on the ICF, with these being: impairment, activity limitation, participation restriction, and well-being (LaTrobe University, 2009). These four domains measure changes pre-service and post-service with a level of difficulty scale ranging from zero, the most severe impact on the service user, to five, being no difficulty for the service user (Unsworth, 2005).

Assessment of AusTOMs against criteria

The AusTOMs do focus on the outcomes experienced by a service user and are capable of identifying broader life outcomes (with five of the twelve scales focused on such outcomes e.g. interpersonal interactions and relationships). However, the scales that focus on functional outcomes tended to be used more frequently by occupational therapists than scales that focus on broader life outcomes (Unsworth, 2005).

The AusTOMs' overall purpose is to capture the changes resulting from therapy provision (Perry et al, 2004), meaning that the outcomes proposed during service user admission are typically service provider-defined rather than service user-defined outcomes. Further, the AusTOMs require "clinical judgement" (p. 1) and are thereby designed to be rated by the professional rather than the service user (Morris, Dodd & Taylor, 2004). This means that that the service user is unable to provide their subjective, self-reported perspective around service provision and its impact on their life.

The AusTOMs do not identify any barriers and enablers to outcomes (Unsworth, 2005), and therefore provide little opportunity to use the collected data to improve services delivery. Further, the instrument is not designed for accessibility.

Canadian Occupational Performance Measure (COPM)

The Canadian Occupational Performance Measure (COPM) was originally developed in 1991 to be used by occupational therapists to measure occupational outcomes for people with disabilities (COPM, 2005). The COPM has been revised three times, with the last edition published in 2005. The COPM is administered by an occupational therapist in a semi-structured interview format with the service user. It aims to identify personal needs and wants in occupational performance, and the relevant barriers associated to this. The tool has three broad domains: self-care, productivity, and leisure (Law, Baum & Dunn, 2001). A 10 point rating scale is used to assess 'performance' and 'satisfaction' during the initial assessment, and re-assessment after the occupational therapy intervention has been provided (Donnelly & Carswell, 2002).

Assessment of COPM against criteria

The COPM is frequently used within the occupational therapy field, and is not often used by other disciplines for purposes other than occupational therapy practice (Chesworth et al, 2002; McColl et al, 2000; Donnelly & Carswell, 2002). Therefore, the COPM is disciplinary specific, and consequently fails to meet Scope criterion no.2 (see Table 1).

Although the COPM was developed to be used as an outcome measurement tool, the COPM is often used as a diagnostic tool in occupational therapy practice (for example, Dagfinrud et al, 2005; Samuelsson, Tropp & Gerdle, 2004; Brincat, 2004).

It has also been identified by the COPM's authors (McColl et al, 2005) that the use of the COPM with

people with intellectual disabilities may be problematic for a number of reasons, including the inaccessible format of the tool (i.e lack of pictures or images), and the potential for the service user to have difficulty in comprehending a numerical rating scale.

However, one of the COPM's strengths is the use of 'performance' and 'satisfaction' as indices to assess outcomes from service delivery. 'Performance' in occupational outcomes measurement is perceived as gaining ability to do a task that could not be done previous to the intervention, where 'satisfaction' is perceived as how satisfied the service user is with the outcomes from the intervention and rated as "not satisfied, or extremely satisfied" (Wressel et al, 2003: p.497). The use of these two indices identifies the need to capture not only the performance of the intervention, but to capture the service user's subjective understanding of the service's broader outcomes, for example, the applicability of the intervention to daily life and the process by which the intervention occurred.

The Personal Wellbeing Index (PWI)

The Personal Wellbeing Index was developed by Cummins and Lau (2005) to capture a person's subjective wellbeing. The tool captures subjective data across eight life domains, including: standard of living, personal health, achievement in life, personal relationships, personal safety, community-connectedness, future security, and religion/spirituality (McGillivray et al, 2009).

The PWI is an improved version of the Comprehensive Quality of Life Scale (ComQol), which was developed earlier by Cummins (1997) to measure both subjective and objective quality of life. The major difference between the ComQol and PWI is the removal of the objective wellbeing measurement items, and the removal of the multiplication of the concepts around 'importance' and 'satisfaction' (Cummins, 2002). The tool uses an 11-point likert scale to identify an individual's subjective wellbeing across each domain (McGillivray et al, 2009).

Assessment of PWI against criteria

The authors of the PWI acknowledge the importance of collecting outcome data subjectively (McGillivray et al, 2009). Therefore, the parallel version of the PWI, developed specifically for people with intellectual disabilities and other cognitive impairments (PWI-ID) captures the individual's subjective perspective of their wellbeing, rather than by-proxy via support workers or family members. The PWI-ID has adopted accessibility design characteristics to enhance the opportunity for people with intellectual disabilities to respond to items; however, the time required to administer the tool is quite lengthy, taking 45 minutes on average to complete (McGillivray et al, 2009). Whilst the PWI-ID may be somewhat accessible and focussed on capturing the subjective wellbeing of people with intellectual disabilities, the tool does not capture service goal data, or barriers and enablers to meeting related goals (Cummins & Lau, 2005).

TOOLS RELATED TO LIFE OUTCOMES OF ADULTS WITH DISABILITIES RECEIVING SERVICES AND SUPPORTS

Personal Outcome Measures (POMS)

The Council on Quality and Leadership Canada ([CQL Canada], 2008) first developed an outcome measurement tool titled 'The Outcome Based Performance Measures' in 1993, to both promote 'quality' in the lives of people who use disability services, and also to provide a national accreditation program in Canada (Gardner, Nudler & Chapman, 1997). This tool was then revised in 1997 and renamed as the 'Personal Outcome Measures', or POMs (Gardner & Carran, 2005). There are seven domains: identity, autonomy, affiliation, attainment, safeguards, rights, health and wellness, and 25 sub-domains that are used pre-service to identify each service user's overall desired outcomes from a service (The Council on Quality and Leadership in supports for People with Disabilities [The Council], 1997b). To administer, service users and their supports identify the relevant outcome domains and sub-domains, then modify the chosen sub-domains to reflect their own understanding of their desired outcome. Outcomes are measured by the facilitator/assessor through the use of a post-service decisional matrix, with the overall result summarised by either 'yes', meaning the service user did reach their outcomes, or 'no', meaning the service user did not reach their outcome (The Council, 1997a).

Assessment of POMs against criteria

The POMs have been designed specifically for broad use across disability services and professional service disciplines, and are focused on service user outcomes rather than service outputs or processes (Gardner & Carren, 2005), and in this sense meet some of the established Scope criteria (see Table 1, p.10). However, the tool is quite lengthy, requiring attention to 25 pre-determined sub-domains in order to select and determine person-directed outcomes. The time required to determine outcomes using POMs may not be realistic within service settings that already have limited resources for activities such as planning.

The POMs tool is not available for self-report, rather, it relies on the facilitator's objective perception of whether an outcome has been achieved. This means that the service user cannot formally communicate their subjective perspective on whether they believe the outcomes were achieved, or their satisfaction with the service delivery. Further, because of the discrete measurement method used (i.e 'yes' the outcome is achieved, or 'no', the outcome is not achieved), the POMs are not sensitive to small changes or minor details associated with outcomes.

Lastly, whilst the POMs tool does allow for identification of barriers and enablers to outcome attainment and allows for the identification of broad life outcomes, the overall measurement tool is not likely to be practically useful within disability service settings, due to the inaccessible, lengthy process required to use POMs.

Functioning and Related Health Outcomes Module (FRHOM)

The FRHOM was developed by the Australian Institute of Health and Welfare (AIHW) to capture quantitative health information regarding an individual's level of functioning (2005). The need for the collection of person-centred information that captured both objective and subjective data was emphasised by Bricknell and Madden (2002) during discussion on the development of the minimum health data sets (known as the National Community Services Data Dictionary). The FRHOM's overall purpose was to assist in the development of individual information profiles, through collecting data from a variety of health and community service organisations.

The FRHOM was developed to be consistent with the ICF's domains, and has four matrix tables that capture each of the following: body function, body structure, performance in life areas, and environmental factors (AIHW 2006: p.4). The FRHOM is classified as a data capture tool or measurement tool rather than an assessment tool, with an aim to capture a broad range of information regarding the service user at the beginning of service provision, throughout the process of service provision, and at the completion or transfer of service provision (AIHW 2005). Therefore, for the FRHOM to measure changes, at least two records must be made (i.e. pre- and post-service).

Across the four matrix tables, the FRHOM uses a number of qualifiers to measure outcomes. Included in matrix table number three are indicies of measurement which can loosely be broken into two sub-groups: performance (including level of activity, need for personal assistance, and extent of participation), and satisfaction with participation (AIHW, 2005).

During the FRHOM's development phase, an electronic prototype was designed to ensure accessibility of the tool, and encourage the use of the ICF framework. The prototype was named the eFRHOM (Australian Collaborating Centre, 2006). Although the eFHROM was near the final stages of development prior to implementation, the eFRHOM was abandoned due to the need for certain "technical improvements" (World Health Organisation [WHO], 2007a: p.4), and funding solutions (WHO, 2007b: p.23).

Assessment of FRHOM against criteria

The FRHOM has limitations that prevent it from being useable within disability services to capture service user-directed outcomes. This is mainly due to the tool itself being fairly inaccessible to people with disabilities, for example, the tool is lengthy (as demonstrated in AIHW, 2006), which may mean that the tool would be completed by the service provider or by-proxy (i.e. support person), rather than the service user (AIHW, 2005). Therefore the tool is difficult to capture the service user's subjective perspective of their goal, resulting in the capturing of a service-provider's objective perspective of the service user's goals. In addition, it does not identify barriers or enablers to meetings outcomes.

TOOLS RELATED TO SERVICES DELIVERED VIA GOAL SETTING

Goal Achievement Scale (GAS)

The Goal Achievement Scale (GAS) was developed by Kiresuk and Sherman in 1968 to measure service user outcomes in mental health services. Since its development, the GAS has become one of the most widely used outcome measures across a variety of service contexts, ranging from medicine, for instance rehabilitation (Hurn, Kneebone & Cropley, 2006; Rockwood, 1994; Cytrynbaum et al, 1979); allied health, for instance occupational therapy (McLaren & Rodger, 2003); and human services, for instance intellectual disability services (Chapman, Burton & Reeves, 2006; Jones et al, 2006).

The GAS enables the service user to identify their own expected goals for service in partnership with the service provider (Hurn, Kneebone & Cropley, 2006). Once these goals have been identified, a matrix is developed by which the level of goal attainment can be scored after service has been implemented (Smith, 1994). For example, a score of -2 represents an outcome of less change than expected, 0 (zero) is the expected outcome level (i.e. the service user has reached their expected goal after service implementation), and an outcome of +2 is an outcome of much more than expected (Cardillo & Choate, 1994). Therefore, use of the matrix allows the service user to identify and score service outcomes according to their own subjective perspective.

Assessment of GAS against criteria

The GAS allows flexibility for goal selection, meaning that people with disabilities are not restricted to any particular life domains (Turner-Stokes, 2009), or required to focus on any particular classification concept, for example function, activity, participation or environment.

While some rehabilitation literature suggest that the GAS provides a unique opportunity to engage service users in the goal development process (Tennant, 2007; Turner-Stokes, 2009), the GAS is not overly accessible for people with intellectual disabilities due to the complex methodology (i.e. use of a 5-point anchored likert scale) used to measure outcomes (Chapman, Burton & Reeves, 2006). Further, the GAS goal setting process is likely to be driven by service providers because of their hesitancy to involve service users in such a complex process (Chapman et al, 2006).

The original GAS form does not provide opportunity for identification of barriers and enablers to outcomes (Chapmanet al, 2006). The GAS also requires those involved in the service planning to predict, prior to service delivery, a range of outcomes that the service user may experience as a result of service delivery (Hurn, Kneebone & Cropley, 2006). This is problematic as the tool limits the capture of a range of outcomes from service delivery not previously considered possible or relevant.

OTHER TOOLS – NARRATIVE FOCUS

Most Significant Change (MSC) technique

The Most Significant Change technique (MSC) was originally developed by Rick Davies to capture and evaluate changes occurring as a result of overseas aid development projects (Davies & Dart, 2005). Jessica Dart further developed the MSC by applying the technique to a rural Australian development project, and developing a proforma for capturing change (Dart et al, 2000). The MSC is a narrative-based technique, aimed at capturing rich data around the outcomes from project implementation from stories accrued by a range of project stakeholders. There are many benefits for organisations opting to use MSC, however the key strengths of the MSC include the ability to facilitate continuous dialogue between various project stakeholders, increasing opportunities for learning regarding 'what does and doesn't work' within complex organisations, and promoting a sense of efficacy within participating individuals regarding their ability to contribute to positive change (Davies & Dart, 2005).

Because of the MSC's continuously developing and learning nature, the technique is not restricted by a pre-determined set of outcome indicators that are used in other outcome measurement tools (Davies & Dart, 2005). Respondents are asked to nominate stories of the 'most significant change' occurring in a given context in a given time period. Stories are recorded through a range of methods, including the provision of a scribe. These stories are then analysed (by use of a range of methods) and reported to service providers and others.

Assessment of MSC against criteria

Given its broad nature, the MSC has the potential to capture a broad range of life outcomes. Its intent is to foster self-reported and self-identified outcomes. It has a specific emphasis on identifying the factors, both positive and negative, associated with the change (Davies & Dart, 2005). The technique is potentially quite accessible and has been used in a variety of Australian and international contexts, evidencing its suitability to a wide range of cultures, groups, contexts and literacy levels. However, this accessibility is somewhat dependent on the resources attending its use, such as the provision of scribes and the skill set of such groups. It is not clear how much time would be required to collect or analyse such narratives.

Table 3: Summary of match of tools to Scope working group criteria

SCOPE CRITERIA	OUTCOME TOOLS						
	AUSTOMs	COPM	PWI	POMs	FHROM	GAS	MSC
1. Focus on outcomes, rather than outputs or processes	√		√	√	√	√	√
2. Enable a broad range of outcome types to be named and measured	√		√	√	√	√	√
3. Measure person-defined outcomes. Here, the tool also needed a compatibility with goal oriented / defined interventions		√		√		√	
4. Use indices of measurement that enable the person with a disability to rate the level of their performance and their satisfaction with this (pre and post service)		√			√		
5. Be able to capture participation outcomes as well changes to the environment that facilitated these	√	√			√	√	√
6. Be sensitive to small changes for individuals	√	√				√	√
7. Be brief and easy to use (through design and implementation characteristics) for people with disabilities							√
8. Based on self-report by people with disability, rather than proxy or 'expert' reporting			√				√
9. Be accessible to people with a wide range of disabilities particularly including people with intellectual disabilities			√				
10. Be able to be administered by Scope staff (therapy and psychology practitioners) within their existing time and workload allocations	√	√				√	
11. Require low amounts of time allocation for data analysis						√	
12. Clearly identify the respective perspectives of the person with a disability, the service provider/ practitioner, others in the person's life							√
13. Identify barriers to outcomes		√		√			√
14. Identify enablers to outcomes				√			√
TOTAL	5/14	6/14	4/14	5/14	4/14	7/14	9/14

DISCUSSION AND CONCLUSIONS

The literature surrounding outcome measurement tools currently being used in disability services generates a number of topics for discussion. The literature highlights that capturing outcomes is a complex process. Further, it is evident that the overall purpose of outcome measurement data collection impacts on the way in which tools are developed and implemented. In addition, the literature demonstrates that each tool has strengths and limitations for use within disability services.

Capturing outcomes is a complex process. Reflection on measurement tools currently being used within disability services has highlighted that many stakeholders are involved in capturing outcomes, including service users (people with disability), family and carers of service users, direct service providers, service senior management, allied health professionals, community members, government officials, and quality assurance personnel. Further, the difference between an outcome for a person with a disability, and an output or process indicator of service delivery is not well understood by stakeholders involved in the outcome capture process, and the content focus and use of some 'outcome' measurement tools indicates this ambiguity (e.g. the use of the Canadian Outcome Performance Measure, see Dagfinrud et al, 2005).

The process of capturing outcomes for people with disabilities is made more complex through the number of different underlying purposes for capturing outcomes within the measurement tools. For example, while the AusTOMs overall purpose is to capture outcomes service users experience as a result of an allied health intervention (Unsworth, 2005), an explicit purpose of implementing the POMs in certain organisations is to capture data to substantiate future quality assurance strategies (Gardner & Carran, 2005). The GAS aims to capture outcomes specific to the service user (Jones et al, 2006), while the FHROM aims to capture individualised data to inform national health interventions (AIHW, 2005). Another common purpose of capturing outcomes in disability services is for 'benchmarking' or comparing the effectiveness of services across services or programs. These distinct purposes may or may not align with the purpose of outcome capture required in other contexts thus limiting the effectiveness of outcome measurement instruments when transferred to other contexts (eg different service settings and organisations).

This literature review demonstrates that the type of data captured, and how it is captured, varies according to each outcome instrument. In most instances, data is recorded by service providers or external observers about the assumed outcomes for service users (eg the POMs and the FHROM). In the field of allied health services, data is typically recorded by the health professional (service provider) based on their professional judgement (eg. the AusTOMs). Few tools enable outcomes to be self-reported by the service user; some allow for this engagement though do not require it (eg the GAS), and others are specifically designed to capture

the subjective view point. The PWI specifically ensures that the person with a disability is able to self-report, rather than by proxy, and that the tool is accessible to people with intellectual disabilities. Overall, though, there is little focus on methods of enabling or affirming the self-report of people with disabilities about their own experiences and outcomes.

While broader literature (eg Ritchie et al, 2001) reinforces the importance of collecting information about the ingredients of change or areas of service improvement needed to increase positive outcomes, most tools do not provide mechanisms to collect this data. In this sense, their usefulness within disability service provision contexts is limited as they fail to provide "monitoring which leads to action" (Ritchie et al, 2001: p.177). A focus on identifying barriers and enablers to outcomes is most evident only in two tools (POMs and MSC), others fail in this regard (though it should be noted that this was not their explicit purpose).

Finally, the current policy environment in disability, both internationally and within Australia (and more specifically Victoria), requires a focus on whole-of-life outcomes for people with disabilities generated through both individual supports and structural/environmental change. Outcome measurement instruments are needed that engage with a broad range of outcome areas (for example, across the fifty Articles of the UN Convention on the Rights of Persons with Disabilities). Few tools enable this breadth, and indeed data collection and analysis across this range is likely to pose problems, particularly in regard to juggling the tension between the ability to customise outcomes to suit individual priorities, and the need for clear categories of analysis that can be generalised across larger groups and populations.

This discussion focuses on a number of the issues to be considered when adopting or developing an outcomes measurement data collection instrument for use in disability services. The Scope working group's list of criteria for an outcomes measurement instrument further delineates these and others. Given the complexity of requirements and issues, it is clear that any instrument will have both strengths and limitations, and include a number of 'trade-offs' between criteria. This literature review identifies that no current instrument reviewed here suits the purposes of outcomes measurement as defined by Scope. As a result, the new instrument, the Measurement of Services and Supports (MOSS) tool, has been developed to respond to identified criteria, draw on learnings from existing in instruments, and meet the requirements of the current policy and legislative environment.

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