

Participatory Monitoring of Community-Based Rehabilitation and other Disability-Inclusive Development Programmes: the Development of a Manual and Menu

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ABSTRACT

Purpose: *This paper describes a three-year research project leading to the development of the CBR Monitoring Manual and Menu (MM&M). The MM&M is a practical toolkit that meets the needs of CBR managers and stakeholders, and is consistent with the philosophy of CBR and community-based disability-inclusive development. It is designed to produce meaningful and locally useful information and data, based on international data standards where possible, to enable aggregation at regional, national and international levels.*

Methods: *Five complementary workstreams of research were carried out from 2011 to 2014: 1) literature review and analysis; 2) participatory action research with CBR stakeholders; 3) analysis and refinement of validity of concepts and structures; 4) consultation and review; and 5) synthesis of results. This article documents the method and key results of each of the five workstreams, and the lessons learned along the way.*

Results: *The MM&M is now freely available on-line at <http://sydney.edu.au/health-sciences/cdrp/projects/cbr-monitoring.shtml>. Collaboration among*

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members of the development team continues, chiefly via an on-line group to which new members have been welcomed.

Conclusion and Implications: *At the time of writing, the MM&M is the only international monitoring product, known to the authors, that consciously sets out to reflect both a 'bottom-up' and 'top-down' perspective of monitoring information and data. To achieve this for a complex programme such as CBR, and to align with its principles, it was essential to use a multi-component and multi-stage strategy for tool development, involving a diverse multidisciplinary team including collaboration with CBR stakeholders.*

Key words: *monitoring methods, monitoring tool, evaluation, International Classification of Functioning, Disability and Health (ICF)*

INTRODUCTION

While Community-Based Rehabilitation (WHO, 2004; WHO, UNESCO, ILO, IDDC, 2010) is a valued development approach, there is inadequate evidence to demonstrate its efficacy (Finkenflugel et al, 2005; Hartley et al, 2009; WHO, 2011), due in part to a lack of suitable data collection tools (Lukersmith et al, 2011). To be consistent with the CBR guidelines (WHO, UNESCO, ILO, IDDC, 2010) and other relevant global standards and principles, the starting point for building evidence should be to encourage monitoring that is participatory, locally controlled and owned, and empowers stakeholders with information they can use to improve programme quality, management and sustainability. The CBR Monitoring Manual and Menu (MM&M) has been developed to provide a practical toolkit that meets the needs of CBR managers and stakeholders, and is consistent with the philosophy of CBR and disability-inclusive development.

Objective

The authors' objective was to develop a CBR monitoring toolkit, capable of producing locally meaningful and useful information and data, based on international standards where possible, to enable aggregation at regional, national and international levels. The global standards and principles which guided the work were the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the CBR Guidelines, and the International Classification of Functioning, Disability and Health (WHO, 2001; UN, 2006; WHO, UNESCO, ILO, IDDC, 2010). These three different instruments, developed in parallel, have

been informed by changes in global understanding of disability over recent decades (WHO Executive Board, 2014). The UNCRPD mandates practices of signatories to the Convention, to ensure that people with disabilities enjoy the same rights and freedoms as other members of the community. Statistics, collected in appropriate and ethical ways, enable policy formulation and monitoring of progress (Article 31). The UNCRPD also provides the moral compass for research and development in the field. The CBR Guidelines outline the scope and nature of CBR and give guidance on implementation. Built on the general principles set out in the UNCRPD (Article 3), the CBR Guidelines add two further principles relating to the need for empowerment and sustainability. Finally, the ICF is the international standard framework and classification for functioning and disability, providing the technical infrastructure and building blocks for recording and measurement. Consistent with the UNCRPD, the ICF has a broad view of functioning (participation, activities, body functions and structures) across all domains of life, and requires an accounting for environmental influences.

This paper describes a three-year research project to develop a toolkit for monitoring CBR and other community-based inclusive development programmes, involving a partnership between researchers at the University of Sydney and CBR stakeholders in Asia and the Pacific. The toolkit comprises a Manual and a Menu which offer guidance to CBR managers and other stakeholders to design and collect locally relevant information and data. The Manual provides a step-by-step process for developing a monitoring plan and designing monitoring activities to meet local information needs using items from the Menu. The Menu contains information items and data items, grouped by topic, from which users can select those appropriate to their needs. The items were developed with reference to international standards, and drew on the local knowledge and experience of collaborators. This paper documents the method that produced the MM&M, and the lessons learned along the way.

METHOD and RESULTS

To work with these objectives and principles, a multi-component and multi-stage tool development strategy was devised and implemented by a diverse multidisciplinary team. Collaboration with CBR stakeholders was critical and involved people from Disabled People's Organisations (DPOs), government and non-government health and community services, and community-based organisations from 7 countries in Asia and the Pacific. Sydney team members

provided experience and knowledge in CBR and community development, service provision, teaching, statistics and information development.

Five complementary workstreams of research were carried out from 2011 to 2014: 1) literature review and analysis; 2) participatory action research with CBR stakeholders; 3) analysis and refinement of validity of concepts and structures; 4) consultation and review involving all collaborators and a wider audience, including an advisory group established in the final year of the project; and, 5) synthesis of results from all workstreams.

Table 1 gives an overview of the method, highlighting cross-fertilisation between the workstreams and the iterative refinement of research outputs. The following sections outline the methods and key results for each of the five workstreams.

Table 1: Method and Key Milestones: Overview

	Timeline	June-Dec. 2011	2012	Jan.-June 2013	July-Dec. 2013	Jan.-May 2014
Five research workstreams	1. Literature Review and Analysis	Early literature analysis suggests need for consistency and standard tools.	Second literature review begins to yield information items relevant to CBRM&E.	First paper (Lukersmith et al, 2013) published, indicating lack of standards for CBR monitoring & evaluation.		Second paper (Madden et al, 2014a) published, demonstrating relevance of ICF to CBRM&E.
	2. Participatory Action Research	Workshop with Asian colleagues. MM 2011 compiled at workshop. Workshop programme informed later Manual drafts.		Workshop with Pacific colleagues. MM2013 (March) compiled at workshop. Workshop programme and discussions inform Manual drafts.		

3. Analysis and Refinement of Validity		Sydney team checks for the logic of the MM2011 structure with data standards: information models and data collections.	Alignment with CBR Matrix checked.	ICHI mapping: Comparison of 'service activities' of MM2013 (July) with draft ICHI. Online survey on MM concepts and categories.	
4. Consultation and Review				MM2013 (July) sent to Advisory Group and collaborators (August). Alpha draft of MM&M sent to Advisory Group (November).	Comments from Advisory Group, collaborators, and external reviewers. Work with collaborators on examples boxes.
5. Synthesis		Sydney team starts to allocate items from the 2nd literature analysis, to the framework of MM2012, revise Menu headings for missing concepts.	Synthesis of MM done collaboratively in March workshop. Work on incorporating information items from 2nd literature analysis into MM completed.	Both the ICHI mapping and analysis, and the online survey results led to further refinements of MM.	Iterations of revisions of MM&M based on synthesis, and comments and reviews. Work of research team on Appendices of Manual.
MM&M V1.0 published in May 2014 on http://sydney.edu.au/health-sciences/cdrp/cbr-monitoring.shtml and presented at WHO meeting (London)					

Workstream 1: Literature Review and Analysis

A literature review on monitoring and evaluation in CBR commenced in 2011, with the first project publication in 2013 (Lukersmith et al, 2013). Thirty-six articles met search criteria and were subject to 2 analyses that are briefly outlined here. The first analysis found that systematic measurement of CBR programme outcomes was problematic due to a lack of standard tools and methods, and a consequent lack of data detail and consistency (Lukersmith et al, 2013). Local

control over monitoring and data collection across programmes and time were not accepted practices. Evaluation was commonly conducted by an external person, often from the same country, together with international researchers. The review concluded that there was a need for more rigorous and consistent monitoring and evaluation practices (Lukersmith et al, 2013).

A second analysis of the literature, reported in 2014, explored the potential relevance of the ICF for CBR monitoring (Madden et al, 2014a). Information items were extracted from the literature and coded to ICF domains and categories. Approximately one-third of the identified information items related to concepts of functioning, disability and environment, and could be coded to the ICF. These items were spread across the ICF classification, with a concentration on Activities and Participation (49%) and Environmental Factors (42%). The review concluded that the ICF is a relevant and potentially useful framework and classification, providing building blocks for the systematic recording of information about functioning and disability for the monitoring and evaluation of CBR. (The 'non-ICF' items were preserved, so that both sets of information items from the literature could inform the construction of the Monitoring Menu.)

Key results from the literature analyses demonstrated that for CBR monitoring and evaluation there was:

- A lack of consistency in tools and methods used;
- Limited involvement of CBR stakeholders; and,
- Relevance of the ICF to underpin monitoring and evaluation.

These analyses of the literature also produced lists of information items to inform the Monitoring Menu.

Workstream 2: Participatory Action Research

The second workstream comprised 2 workshops and ongoing interactions with CBR stakeholders in 7 countries in Asia and the Pacific.

The First Workshop with Collaborators from Asian Countries

Stakeholders from Southeast Asia (Lao-PDR, Vietnam and the Philippines) attended a four-week CBR capacity-building workshop in 2011. The programme was planned to build capacity in CBR and related information systems. It provided 'train the trainer' workshops on CBR, the ICF and information development. The

programme included three days of visits to urban and rural community-based services, and a two-day seminar on CBR which involved guest speakers and presentations from workshop participants.

The interactive workshop led participants through structured exercises in 'information design' to encourage reflection on the key features of their programmes and to identify the information needed for programme improvement and sustainability. Information needs were identified during a series of small group discussions about why information is needed (purpose); who will use it; what information items are actually required; and how information would be captured, reported, stored, used, and disseminated (Madden et al, 2013). The results of these discussions were then compared and combined, with iterative whole group discussions about how best to group the information items identified.

This work resulted in 60 information items, grouped into 5 categories: Outcomes for people; Profile of people; Services provided; Staff and skills; and, Unmet needs. These organised lists constituted the first draft Monitoring Menu - the MM2011. [At an early stage it had been thought that the monitoring toolkit might involve something similar to a data dictionary with standards. However the term 'menu' was considered both clearer and more representative of likely contents, with some items descriptive rather than tightly-specified data items.] Final sessions drew all the work together as participants drafted and discussed plans for further work of their own on monitoring.

Key results from the first workshop were:

- The term 'Menu' being adopted, clarifying that any combination of information items could be selected for use to meet the needs identified; and,
- The first draft Monitoring Menu- the MM2011 (see Table 2).

The Second Workshop with Collaborators from the Pacific

Stakeholders from the Pacific (Papua New Guinea, Timor Leste, Fiji and the Solomon Islands) attended a three-week workshop in 2013. The purpose was to build capacity in monitoring and information management, and to develop the next iteration of the Monitoring Menu suited to participants' organisational and country needs. As with the first workshop, related topics and other presenters were introduced, and there were two days of field trips to community-based services.

In the first week, activities focussed on sharing information about countries, programmes and international developments, and building capacity in CBR, the ICF and information design. In the second week, participants determined local information needs, using the same methods applied at the first workshop: discussions of 'why, who, what and how' in intensive small group sessions.

This work resulted in 79 information items, grouped into 8 categories: Service activity; Resources; Outcomes; User; Environment; Barriers; Needs; and, Partnership/Network. The MM2011 and MM2012 (see Workstream 3) draft Monitoring Menus were then revealed to the Pacific participants and discussed. The 2013 workshop items were then mapped into the MM2012 framework to produce a new iteration of the Menu.

This blended framework was reviewed in the third week. Debate focussed on how to represent 'community'. After several attempts, it was concluded that the idea of 'community' runs through many categories and was therefore a key cross-cutting theme, rather than a separate category of information items in the Menu. Ideas for a Manual to accompany the Menu were also canvassed at this stage (see also Workstream 3).

A final consensus-seeking session resulted in MM2013 (March) (see Table 2), which reflected a synthesis of the work to date: the results of the two workshops and the items from the literature analysis incorporated until that stage.

Key results from the second workshop were:

- Finalising the naming of the Monitoring Manual and Menu (MM&M);
- Significant expansion and refinement of the contents of the Menu; and,
- Initial identification of content for the Manual.

Table 2: Structure of successive drafts of Monitoring Menu (from final to earliest versions)

Final M&M V1.0

Person	Programme
<i>P1 Person – Personal profile and History</i>	<i>O1 Organisation – Purpose, Structure & Strategy</i>
<i>P1.1 Name</i>	<i>O1.1 Purpose statement (e.g., Goals; Geographic scope; Principles)</i>
<i>P1.2 Address</i>	<i>O1.2 Structure (e.g., Sector; Structures and roles)</i>
<i>P1.3 Geographic location</i>	<i>O1.3 Strategy (e.g., Priorities; Service plans; Key relations, Community linkages and stakeholders; Information, reporting, communication)</i>
<i>P1.4 Age – Date of birth</i>	<i>O2 Organisation – Resources (e.g., Funding/income; Expenditure; Stakeholders and community links; Knowledge resources)</i>
<i>P1.5 Gender</i>	<i>O3 Organisation – Environment (e.g., Government and community commitment; Community knowledge of disability and support of CBR; Socio-economic and cultural profile of community)</i>
<i>P1.6 Cultural or other group</i>	<i>O4 Organisation – Outcomes (e.g., Sustainability; Environmental strengths)</i>
<i>P1.7 Language</i>	<i>A1 Activities – What is done</i>
<i>P1.8 Health condition/diagnosis</i>	<i>A1.1 Planning and managing the activities (e.g., Planning and preparing services)</i>
<i>P1.9 Health-related history, factors and behaviours</i>	<i>A1.2 Activities targeting people and families (e.g., Counselling; Therapy; Financial aid; Equipment, assistive devices; Education and skills development; Support in participation)</i>
<i>P1.10 Date(s) of onset of health condition, disability</i>	<i>A1.3 Activities targeting the community (e.g., Education – community and groups; Improving access to mainstream services)</i>

<i>P1.11 Education</i>	<i>A2 Activities – Outcomes (e.g., How are services regarded? Do services adhere to CBR principles? Are services effective?)</i>
<i>P1.12 Employment status</i>	<i>W1 Workforce – Personal profile of staff (e.g., Volunteer or paid staff; Gender (sex); Payment to staff; Qualifications; Date of entry and exit)</i>
<i>P1.13 Occupation</i>	<i>W2 Workforce – Knowledge and skills (e.g., Goal writing and plan development; Client training; Book keeping; Mobilising the community)</i>
<i>P1.14 Marital status</i>	<i>W3 Workforce – Responsibilities and tasks (e.g., Getting the community involved; Training and education of Staff; Referral)</i>
<i>P1.15 Living arrangements and conditions</i>	<i>W4 Workforce – Training undertaken (e.g., Disability and the needs of people with disabilities; Community development; Assessments)</i>
<i>P2 Person—Functioning and Disability</i>	<i>W5 Workforce – Quality of performance (e.g., Meets targets and demands; Trustworthy; Interest in working in low resource or rural settings)</i>
<i>P2.1 Body functions (Mental functions; Sensory functions and pain; Voice and speech functions; Functions of the heart and blood, resistance to infections, and respiratory systems; Functions of processing food and drink in the mouth, and of the body processing and using the food and drink; Urinary, genital, and reproductive functions; Functions of the nerves, joints, muscles and movement; Functions of the skin and related structures)</i>	

<p><i>P2.2 Activities and Participation (Learning, applying knowledge; General tasks and demands; Communication; Mobility; Self care; Domestic life; Interpersonal interactions and relationships; Major life areas; Community, social and civic life)</i></p>	
<p><i>P3 Person – Environmental factors (ICF) (Products and technology; Natural environment and human-made changes to environment; Support and relationships; Attitudes; Services, systems and policies)</i></p>	
<p><i>P4 Person – Outcomes (e.g., Health; Education; Livelihood; Social; Empowerment)</i></p>	

The Menu contains information items organised into four broad groups: Person; Organisation; Activities; Workforce. Within the groups are subgroups and topics (listed in the Table above) which categorise the items:

- An information item represents a topic or concept, and these may represent a set of related ideas, or one or more data items. In the Menu, some general suggestions are made about what information may be needed and how to record it, using either numbers or text (words).
- A data item is used to standardise the way data are recorded (or represented). A typical data item will have a definition and a set of options (e.g., tick boxes) for recording. This approach has the advantage of making it easy to compile statistics.

In the Menu, each topic or item has short sections on:

- Definition: A proposed definition of the item.
- Significance and use: An explanation of the significance of the item and an illustration of its possible use in monitoring.
- Recording guide: Suggestions for recording or coding the information, where possible in ways that enable statistics to be compiled (and related to international standards where they exist). These suggestions or examples can be used or modified to suit local needs.

MM 2013 (July):

Person	<ul style="list-style-type: none"> Person - Personal profile and History Person - Functioning and Disability Person – Environment (ICF) Person – Outcomes
Organisation	<ul style="list-style-type: none"> Organisation – Purposes, Strategy and Structure Organisation – Resources Organisation – Environment Organisation – Outcomes
Services	<ul style="list-style-type: none"> Services - Activities of service provision Services – Service outcomes and quality indicators
Staff	<ul style="list-style-type: none"> Staff - Skills and staff characteristics

MM 2013 (March) (structure attempting matrix)

Person	Organisation	Services Provided	Staff
Personal Characteristics and History	<ul style="list-style-type: none"> Strategy, purposes, management philosophy Organisational roles and structures Broad programme design (e.g. Goals) 	Activities of service provision	<ul style="list-style-type: none"> Skills and staff characteristics Roles, Training
Functioning (Body Functions and Structures, Activities and Participation).	Resources, expenses, sustainability	Service Outputs	Staff Outputs

Environmental factors (e.g., family, community....)	Environment	Environment	Environment?
Community	Community/ linkages	Community/ linkages	Community/ linkages
Outcomes Needs	Outcomes	Outcomes Needs	Staff performance

MM 2012

Person	Organisation	Staff	Services
Characteristics (e.g. date of birth, sex,	Strategy, purposes,	Skills and staff characteristics	Type of service provided
Functioning (Body Functioning and Structures, Activities and Participation)	Resources		
Environmental Factors (e.g. family, community ...)	Environment		
Outcomes – possibly constructed multidimensional items	Outcomes (written as strengths and indicators of success)	Staff performance measures (outcomes)	
Needs (met, unmet) – possibly constructed multidimensional items	Sector – government/non-government, etc		

MM 2011

<p>Service or organisation profile</p> <p>Personal information</p> <p>Environment - family and living situation</p> <p>Functioning</p> <ul style="list-style-type: none"> • Body functioning • Activities and participation

Workstream 3: Analysing and Refining Validity

This workstream was designed to develop and enhance the validity of the Menu: its structure (including headings and their meaning, inter-relationships, and hierarchical levels) as well as content.

Reference to Data Standards and Collections

In order to improve the logical structure and ontology of the Menu, the 'list-like' structure of the MM2011 was compared with Australian information models (Australian Institute of Health and Welfare –AIHW,1995; Madden and Hogan, 1997) and disability and health service data collections (AIHW, 2009, 2010).The questionnaires used in a CBR research programme in India (Biggeri et al, 2012) were also checked for headings and types of items.

This work led to changes in the list-like structure of MM2011 towards clearer and more distinct headings in MM2012 (see Table 2). For example, the MM2011 had a heading 'service or organisation profile' which includes items about 'services received' and 'staff involved'. Based on comparisons with other models and their definitions, MM2012 separated 'organisation' from 'services' and 'staff', clarifying that these are three different entities.

Other Australian references were also used to inform the work on 'definition', 'purpose/significance', and 'recording guide' provided in the Menu for each information item (AIHW, 2003-2004, 2014). In the final stages of the Menu preparation, international data standards (e.g., the UN data glossary for education information items: <http://data.un.org>) were sought, to further inform and elaborate on the 'definition' and 'recording guide' for each item.

Key results from this workstream component were:

- Improved structure of the Menu – MM2012;
- Use of international standards for Menu items; and,
- Guidance for users included in the Menu.

Alignment with CBR Matrix

Two initial steps were taken to promote alignment of the draft Menu with the CBR Guidelines.

The first step checked whether the information items contained in MM2013 (March) aligned with components in the CBR Matrix, to ensure conceptual

consistency. An example is the information item 'community group or organisation membership', which was linked to the CBR Matrix component 'Empowerment' and related elements (e.g., self-help groups and disabled people's organisations). The second step involved a detailed mapping of the structure of topics and outcomes contained in MM2013 (March) to the structure and language of the CBR Guidelines and Matrix where possible.

Key results from the alignment with the CBR Matrix were:

- Confirmation of conceptual consistency between information items contained in the Menu and the CBR Guidelines and associated CBR Matrix; and,
- CBR Matrix components were used to structure outcomes in the 'Person' grouping of information items in the Menu.

ICHI Mapping

The World Health Organization's draft International Classification of Health Interventions (ICHI) covers interventions across all sectors of the health system (WHO, 2013). ICHI sits alongside the ICF and ICD (International Classification of Diseases) as a member of the WHO Family of International Classifications, an internationally endorsed suite of health classifications that provide a 'common language' for recording, sharing and comparing information on health.

The 2013 Alpha version of ICHI and the MM2013 (July) were used to assist in evaluating the organisation and specification of information items in the Menu sub-group 'Activities: what is done' (see Table 2 – final form of Menu). Each intervention code in ICHI is described in terms of three axes: Target, Action and Means; each axis comprises a list of descriptive categories. Relevant ICHI intervention codes and axis categories were identified for each Menu item. This generated a list of relevant ICHI intervention codes and axis categories, accompanied by comments on the 'fit' between ICHI and the CBR information items, e.g., in terms of level of detail and underlying concepts.

In most cases, intervention codes in ICHI were described at a finer level of detail than the MM2013 (July) items. For example, ICHI contains separate codes for counselling addressed to specific topics (e.g., interactions and interpersonal relationships, major life areas, attitudes of others), while Menu items were less specific as to topic (e.g., 'social counselling', 'provide counselling'). Several ICHI Action categories were identified as relevant to describing MM2013 (July) information items (e.g., 'Education', 'Provision', 'Referral', and 'Community development').

The research team agreed that items in the Menu should be expressed in a language and at a level of detail meaningful to CBR researchers and programme providers, and should not be reformulated to achieve a better fit with ICHI. Nonetheless, the formal structure of ICHI helped to clarify the underlying conceptual dimensions of the Menu items and make decisions about grouping of items. For example, the possibility of having separate 'Education' and 'Skills development' items was discussed, as 'Education' and 'Training' are separate Actions in ICHI. However, it was decided that to best reflect how CBR services are delivered, 'Education and skills development' should be combined but distinguished as to whether the service is provided to the person or the family. As a result of the joint work, ICHI developers recognised the need for ICHI to be adaptable for use at varying levels of detail in order to increase its utility in low-resource settings.

Key results from the ICHI mapping exercise were:

- Review and refinement of Menu items in the group 'Activities: what is done', in terms of how these items were expressed and grouped.

On-line Survey: Exploring and Developing Content and Construct Validity

An on-line survey was conducted to elicit expert feedback on categorical content, face validity, differences of interpretation, and topic clarification, for MM2013 (July). A convenience sample of 24 experts were drawn from the professional connections of project researchers, networks of CBR professionals and professionals from other disability inclusive programmes and participated in the survey anonymously.

The survey included a web-based sorting exercise to:

- Investigate inter-rater agreement on the categorisation of selected information items using examples considered to be of key common interest to CBR programmes, taken from Menu categories not yet fully clarified; and,
- Generate respondent descriptions of menu subgroups and topics (Person Outcomes; Organisation Outcomes, Organisation Purpose; Staff).

Inter-rater agreement results are summarised in Box 1. (See Table 2 for definitions of 'groups' and 'topics' etc.)

Box 1: Inter-rater Agreement on Assignment of Items to Subgroups

Person Outcomes: There were five answer options (health, education, livelihood, social, and empowerment, corresponding to the CBR Matrix components), plus “do not know / not applicable”. For the 20 items investigated, the majority of respondents agreed with the assignment in the Menu for all but 5 items. Some of these items appeared ambiguous, e.g., there was confusion between ‘livelihood’ and ‘empowerment’, and ‘social’ and ‘empowerment’, with the other 3 items creating confusion generally with relatively large ‘don’t know’ responses. These 5 items were amended or dropped from later versions of the Menu.

Staff: There were five answer options (personal profile, training, skills, responsibility and tasks, and, qualities and performance), plus “do not know / not applicable”. For the 20 items investigated, the majority of respondents agreed with the assignment in the Menu for all but 6 items. These 6 items seemed particularly confusing, with responses distributed across three categories from among the following four: training, skills, responsibilities/tasks and qualities/performance. These problems were mainly remedied by means of definitions and explanations in the Menu.

Organisational Outcomes: There were two answer options (sustainability, environmental strengths), plus “do not know / not applicable”. For the 20 items investigated, the majority of respondents agreed with the assignment in the Menu for all but 6 items. The responses to these 6 items indicated ambiguity between two subgroup headings and, in almost all cases, an overflow into ‘don’t know’. Again, definitions and clearer terms resulted from this information, and the creation of a more hierarchical structure of subgroups and items, thus reducing the number of subgroups.

Organisational Purpose: There were six answer options (objective, scope and target group, plans and priorities, principles, policies and processes, and communication), plus “do not know / not applicable”. More than half of the responses did not correspond to the assignment in the Menu and betrayed confusion across all options. These results led to considerable discussion and reorganisation. In the final Menu, only 3 topics (Organisation purpose, strategy, and structure) were retained in this subgroup; that is, all the problematic subgroups were removed and the title descriptors became the subgroup headings.

Following the sorting task, respondents were asked two questions, germane to their direct experience with the newer concepts for 'staff' and 'organisation': 'Describe the topic in one sentence'; and 'Do you have any suggestions or comments about the topics or the items?'

Answers to the first question provided raw material for the development of definitions in these topics. The second provided insight into any ambiguity in concepts and any lack of clarity in the items.

Key results of the survey included the following changes to the Menu:

- Reinforced the need for definitions (and in some cases suggested useful draft wording);
- Clarified the meanings of some information items, and the need to group items with similar meaning together (e.g., the items 'living conditions' and 'standard of living') or, to relocate them (e.g., training of staff, volunteers, family);
- Indicated the need to restructure the 'Organisation' group;
- Confirmed the relative ease of sorting items into the headings for 'Person Outcomes'; and,
- Confirmed the value of summative information for outcome categories (Person, Organisation, Services).

Workstream 4: Consultation and Review

Consultation and review continued throughout, involving the Sydney team and all the 2011 and 2013 workshop participants, seeking and combining comments on all drafts and working together to develop case studies which are included as examples in the Manual. An on-line discussion group was established with these collaborators and later expanded to include others who were interested to participate.

The Sydney team also carried out intensive internal review, with team members providing detailed comments and revised text for successive drafts of the Manual and the Menu. Meetings were held to solve problems; for example, a workshop to resolve a residual concern that the topic of 'community', discussed at the 2013 workshop, had not been adequately represented. The representation of entity relationships diagrammatically provided a breakthrough in the workshop, resulting in Appendix 4 of the Manual (WHO, 2013). This illustrates three cross-

cutting themes, based on the CBR Guidelines and consideration of themes in the MM&M: Empowerment; Participation, inclusion and mainstreaming; and Community. Examples of key questions and related information items for these themes are illustrated for the fields of health, education and livelihood (other components from the CBR Matrix).

An advisory group was established for the closing stages of the project, from mid-2013 until finalisation in 2014. Membership of the group included representatives of CBM, other CBR experts, and representatives of the Sydney team and the Asia and Pacific collaborators. They reviewed final drafts of both the Manual and Menu, via email, teleconferences and Skype calls. Reviews of the final draft MM&M were also requested of a wider group of CBR practitioners and researchers, with useful comments being received from four people from Handicap International, University of Cape Town, the World Confederation of Physical Therapists and the Nossal Institute.

Key results of consultation and review were that:

- Wider advice and review in the later stages brought fresh views and expertise as further quality control; and,
- Consultation and collaboration were recognised as productive features of the method, ensuring that multiple skills and perspectives informed the work throughout.

Workstream 5: Synthesis of Results from all Workstreams

Synthesis comprised iterative drafting of successive versions of the Menu and Manual from mid-2013. Frequent Sydney team meetings and Skype calls with collaborators in Asia and the Pacific enabled collaborative work in synthesising the results of all workstreams to date (see Table 1 for an overview of the five workstreams and Table 2 for some successive draft structures of the Menu).

Iterative Refinements of Successive Menus: Absorbing Items and Reviewing Structures

The Sydney team, over several months (from mid-2012 to mid-2013), incorporated the results of the second literature analysis (Madden et al, 2014a). The ICF items were considered to be well-categorised and the priority was to enhance the structure and content of the Menu in relation to the other non-ICF items identified in the analysis. This was a gradual and iterative process, involving

allocation of 1,707 'non-ICF items' to the framework of MM2012 (wording of the information items from the MM2011 was retained in MM2012) (see Table 2). As the information items were allocated, the structure of MM2012 was revised to accommodate missing concepts. While all items (ICF and non-ICF) were initially added to the Menu, only frequently-used ideas and items or major concepts were used to revise category headings; items which appeared only once or twice in the literature and never in workshops were excluded. The process to absorb items from the literature review was completed after the Pacific workshop (MM2013, March). One author (RM) prepared the initial allocation of these items, with another (SL) in 2013 checking the structure and content, and consensus being achieved in personal discussion.

Key results of the synthesis of the information items were:

- Incorporation of 'information items' from the second literature analysis into the Menu;
- Agreed nomenclature of 'groups', 'subgroups' and 'topics', to signify levels within the hierarchical structure of the Menu (see Table 2); and,
- Iterative revision of the structure of the Menu, combining work on incorporating items with the results of all other workstreams.

Successive Drafts of the Manual

Ideas relevant to the Manual were first discussed at the 2011 (Asia collaborators) workshop at which a draft list of information and resources was developed. This list was further extended and refined at the 2013 (Pacific collaborators) workshop. A draft outline of the Manual was then circulated to the authors' collaborators and advisers for comment (see Workstream 4). Key features that collaborators sought in the Manual were: a question and answer format, inclusion of principles (including about involving stakeholders, particularly people with disabilities), explanations (e.g., the difference between monitoring and evaluation), templates and examples, definitions and links to resources, and plain English language where possible.

Drafts of the Manual were assembled and revised in 2013-14. The Manual drew on the successful workshop elements, the principles of CBR, and the suggestions of those who collaborated with the authors. Each collaborating country provided a local example which was included in the Manual.

The MM&M was published on the web in April 2014 (Centre for Disability Research and Policy, 2014).

DISCUSSION

As outlined in the Introduction, the lack of evidence on CBR has been recognised and discussed in the literature over many years. More recently, the discourse has specifically focussed on the monitoring and evaluation methods and tools used by CBR programmes. Recent authors (Lukersmith et al, 2013; Grandisson et al, 2014; Iemmi et al, 2015) report that the methods for CBR monitoring and evaluation are fragmented, and have no common or standardised procedures or tools to enable comparisons. These international studies have all highlighted the urgent need for improved methods, and a common framework and approach to monitor and evaluate CBR programmes. The MM&M toolkit was developed to provide a means to achieve this across programmes and countries.

Such a tool is even more important with new plans for high level of monitoring of CBR and of Sustainable Development Goals (UN, 2015; WHO, 2015). Both these high level monitoring proposals will require sound local data to feed into them. The CBR MM&M is designed to empower stakeholders and build local capability to do so.

Reflecting on the Method

The methodology, as has been outlined and described, was multi-component and multi-stage, and benefitted from a diverse team of researchers and practitioners working together. This was essential given the complexity and participatory nature of CBR itself. Processes were designed to be participatory and collaborative. While all five workstreams were anticipated from the start, new elements were added over the duration of the project because of opportunities which arose or the interests of collaborators:

- Participatory action research: Having the opportunity to interact personally, exchange ideas and gain an understanding of multiple perspectives was a critical foundation for lasting collaboration. One of the concepts which arose from the 2013 Pacific workshop, the 'seven Cs' [Figure 1 of the final Manual (Centre for Disability Research and Policy, 2014)] illustrates the importance of 'collaboration, commitment, cooperation, control, creativity, communication, coordination' to the authors' joint work and the network

qualities that CBR programmes should strive for. The ‘seven Cs’ were also partially represented in a later joint paper (Madden et al, 2014b). Another element was the desire for ongoing contact on broader related topics, which resulted in the establishment of an on-line discussion group, with new members interested in CBR monitoring now joining in.

- Developing and refining the validity of concepts and structures: This component is a standard element of any development work in the monitoring and evaluation field. However, the content of this workstream grew as additional opportunities were identified; for instance, the opportunity to map draft MM&M elements to the newly developing international classification of ‘interventions’ (ICHI).
- Consultation and review: Also a component anticipated from the start, this changed form as the project neared completion. The generosity of the Asian and Pacific collaborators and the broader field meant that the thoughtful insights of experienced practitioners helped shape the final drafts of the MM&M.
- Synthesis of results from the multiple workstreams: To enable the interweaving of results from the different workstreams, timing was important as was the teamwork needed to discuss and cross-check the work throughout the project.

The method overall thus relied on a combination of planned and opportunistic work, and iterative processes of review, revision and synthesis. This resulted in a sequence of increasingly refined draft Menus, and facilitated the preparation of the Manual based on the three years of development, the existing expertise within the research team, and the wider experiences of all collaborators. Future papers will provide further insights into aspects of the MM&M development.

Discussion with New Users

An opportunity for further testing and reflection arose in March 2015, at a WHO workshop in Guangzhou, China. Participants were able to use the methods from the Manual to agree on key information requirements for CBR programmes they nominated, and then identified information items from the Menu to collect the information.

Participants reported that, with few exceptions, ‘relevant items could generally be found’. There was some convergence of information items of interest (see Table

3). Discussion ensued about the possibility of using results from the workshop to agree on indicators for CBR outcomes; the workshop results were combined afterwards to illustrate this possibility (see Table 3).

Table 3: Summary of outcome indicators from China workshop

Information items per Menu group (no. selected)	Person 19 items	Organisation 21 items	Activities 11 items	Workforce 4 items
Candidate groups for indicators of CBR outcomes	P2: Activities and Participation P3: Person's environment P4: Summary outcomes	O2: Organisation – Resources O3: Organisation – Environment O4: Organisation – Outcomes	A1: Activities – What is done A2: Activities – Outcomes	

The China workshop provided evidence of the relevance of the MM&M to the information needs and priorities of CBR stakeholders, and indicated its utility as a tool in drafting a summary indicator list. Such lists could be used by participants for commenting on 'top- down' indicator sets suggested, e.g., by funders or policy makers. This is a key aspect of local empowerment through information. If people at all 'levels' are aware of their information needs, they can negotiate as equals when designing indicators of desired outcomes relevant to all.

Study Limitations and the Challenges for Further Work

This research provides the proof of concept that participatory and empowering processes are achievable and that the MM&M is a useful and valuable monitoring tool. While the 'hard yards' development of the MM&M has been completed, further 'on-ground' testing opportunities are needed, and are being used as they arise.

CONCLUSION

At the time of writing, the MM&M is the only international monitoring product known to the authors, that consciously sets out to reflect both a 'bottom-up' and 'top-down' perspective of monitoring information in CBR and other community-

based disability inclusive development projects. The principles of the UNCRPD and the CBR Guidelines provided key signposts throughout the project. As well as the 'seven Cs', another key ingredient of the development method is 'D' for diversity – the weaving of mixed methods and the involvement of diverse collaborators with experience in Asia, the Pacific, Australia and other countries. The 'bottom- up' aspects of the development emphasised local control and ensured that CBR stakeholders played a primary role in specifying the contents and structure of both the Manual and the Menu. The use of the evidence from research publications (the literature reviews), international frameworks (such as the CBR Matrix), and international data standards (including the ICF) promoted 'top-down' international relevance for the Menu. Use of the MM&M will support locally relevant monitoring, as well as facilitate the production of data possible to be aggregated across local, national and international boundaries.

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Ethics

This paper reports on operational research not requiring ethical clearance.

Declaration of interests

The authors declare that they have no competing interests.

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