THE UNIVERSITY OF SYDNEY

CENTRE FOR DISABILITY RESEARCH AND POLICY

Monitoring Manual and Menu (MM&M)
for CBR and other community-based disability inclusive development programs

Manual

Version 1.0
April 2014

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Centre for Disability Research and Policy
University of Sydney

The Menu is available at
sydney.edu.au/health-sciences/cdrp/cbr-monitoring/

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The University of Sydney team was: Ros Madden, Sue Lukersmith, Sally Hartley, Michael Millington, Charlotte Scarf, Nicola Fortune, Alexandra Gargett and Gwynnyth Llewellyn, of the Centre for Disability Research and Policy.

Key research partners and collaborators were:

Sainimili Tawake	Secretariat of Pacific Community (SPC)	Fiji
Mariaia Matakibau	Ministry of Health	Fiji
Bounlanh Phayboun	COPE	Lao PDR
Sengthong Soukhathammavong	COPE	Lao PDR
Khamko Chomlath	NRC/MoH	Lao PDR
Bounpheng Phetsouvanh	NRC	Lao PDR
Ben Theodore	Department for Community Development	PNG
Peter Sindu	Callan Services	PNG
Susan Goikavi	Callan Services	PNG
Goretti Pala	Solomon Islands College of Higher Education	Solomon Islands
Casper Fa'asala	Gender Alert and DPASI	Solomon Islands
Elsie Ningalo Taloafiri	Ministry of Health and Medical Services	Solomon Islands
Penafrancia Ching	College of Allied Medical Professionals (CAMP), University of the Philippines Manila	The Philippines
Joaquim Soares	Klibur Domin Foundation	Timor Leste
Francisco de Deus Soares	ASSERT	Timor Leste
Phuong Anh Tran Thi	OGCDC	Vietnam
Phuong Tran Thi	OGCDC	Vietnam
Nhan Ha Chan	College of Medicine and Pharmacy	Vietnam
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INTRODUCTION

The Monitoring Manual and Menu (MM&M) provides information on how to develop or improve monitoring, so that programs can collect the information they need. It has been designed for use by community based rehabilitation (CBR) programs and other community based disability inclusive programs. The development process involved collaboration with people involved with CBR, and research on CBR monitoring and evaluation (see Appendix 2). It is ready and freely available for testing or use, and can be downloaded from: sydney.edu.au/health-sciences/cdrp/cbr-monitoring/.

The MM&M is designed for use by program stakeholders

'Stakeholders' includes anyone interested in the success of the program. The most important stakeholders are the people with disabilities (participants) and their family – the people whom the program aims to serve. Other stakeholders are Disabled Persons' Organisations (DPOs), other community groups, advocacy groups (e.g. those that support people with disabilities), community leaders, the organisation responsible for the program and its workforce (volunteers and staff), funders, and other local and regional organisations that work with, or could work with the program (for example women's and youth groups).

The MM&M includes:

1. This **Manual,** which provides guidance on:
    - designing and planning monitoring activities
    - using the Menu
    - other resources and references
2. The **Menu**, which provides:
    - a list of information items
    - guidance on how information may be recorded.

The Manual and Menu go together. Read the Manual first and then use the Menu.

The Menu contains information items organised into four broad groups:

1. *Person*—personal profile and history, functioning and disability, environmental factors, and outcomes
2. *Organisation*—purpose, structure and strategy, resources, environment, and outcomes
3. *Activities*—what is done, and outcomes
4. *Workforce*—training undertaken, knowledge and skills, responsibilities and tasks, and quality of performance

No program is likely to collect information on all the items in the Menu. Users choose items that are relevant to their program goals and information needs.

The MM&M **does not** provide guidance on how to set up a CBR program or disability inclusive development program. You can find information on this through other resources such as the CBR Guidelines: www.who.int/disabilities/cbr/guidelines/en/ (WHO 2010) and other disability inclusive guidelines and manuals (refer to resources & references on p. 26).

PRINCIPLES OF THE MM&M

The following 7 principles are the basis of the MM&M.

Principle 1: Monitoring is locally owned and controlled

Community-based programs decide what information they will collect based on program needs and circumstances. The MM&M empowers people to undertake and manage monitoring activities. This means that program stakeholders need to work out their own monitoring plan, including:

- Why they need information;
- What information they need;
- How the information will be recorded;
- When and where the information will be collected, who will collect it, and how it will be stored;
- How the information will be analysed;
- Who will use the information and how.

The program stakeholders can be in charge of putting the monitoring activities into action and reviewing how well the monitoring activities are going.

Principle 2: Monitoring is participatory and inclusive

The MM&M provides a method for ensuring broad representation of stakeholders, including people with disability, in designing the monitoring plan, selecting information items, deciding how to record information, and implementing monitoring activities. Stakeholders can collect information, and use and report information. Their involvement helps to ensure that monitoring does what it is intended to do and provides the information stakeholders need. When stakeholders are involved, monitoring activities are more likely to be done well because everyone is interested in getting the information.

Include all stakeholders in monitoring in some way. Special attention should be given to the key stakeholders: people with disabilities and their families, and their representative organisations. These groups must have a strong voice in deciding what information is collected, how it will be collected, and for what purpose. Involving key stakeholders will strengthen connections in the broader community. Efforts should be made to include a range of potentially marginalised people to ensure diversity is recognised (e.g. people with intellectual or psychiatric disability, women, older people, youth representatives or people who belong to a cultural minority group); suitable environments must be created for people experiencing difficulties with communication, seeing, hearing, mobility, learning, playing or other activities.

Principle 3: Monitoring information is used for the benefit of stakeholders

It is important to collect only the information that will be used for the benefit of program stakeholders and the organisation. If no one is interested in a particular item of information, don’t collect it.

Information collected should be used regularly. It should be used only for the benefit of people with disabilities and key stakeholders. Monitoring produces information for making decisions and planning, understanding, measuring progress and outcomes, and 'bigger picture' analysis at local, national and international levels. When stakeholders can see how the information is being used, there is incentive for recording quality information.
All stakeholders should have access to monitoring information.

Principle 4: Information that does not change should be collected only once

Many programs already have information systems and processes in place. Monitoring should complement and build on these systems and processes, or replace existing systems, but **not repeat or duplicate.** Also, once information that does not change (e.g., date of birth) is collected, it should be recorded and stored so that a person is not asked the same question again later.

Principle 5: Monitoring is easy and part of everyday routine

Monitoring activities should not require lots of extra work or time. As much as possible, collecting and recording monitoring information should be a part of the usual routine of the people collecting it. Extra time might be needed sometimes, e.g., when all the items of information recorded are brought together for a review or a report, or when a special opportunity to advocate for change requires more information.

Collecting monitoring information should be simple and not hard to learn or sustain. It may be possible to involve other people in collecting the monitoring information, not just the program workforce (e.g., a teacher or parent of a child participant).

Making monitoring efficient
Ticking boxes and recording comments once a week is much easier to do and sustain over several months, than recording information which takes 15 minutes each day.

Principle 6: Use networks to sustain and build capacity for monitoring activities

Sustaining monitoring activities over time is important. One of the ways to sustain and build capacity for monitoring is to use networks, and strengthen and expand partnerships. Networks and partnerships can be in the local, national or international community. Aim for quality not quantity of networks.

The qualities that stakeholders should strive for in their engagement with networks and partners are described in the seven 'C's below (and illustrated in figure 1):

Coordination (bring together and managing between groups and activities)
Commitment (accept responsibility for action involving people with disabilities and monitoring)
Communication (share information and ideas, understanding each other, together use the information obtained from monitoring)
Creativity (use different ideas and existing resources to help to solve problems)
Collaboration (work with each other, build bridges between groups)
Cooperation (combine efforts for greater benefit)
Control (influence and understanding at the local level).

Figure 1: The Seven 'C's: Qualities of networks which produce good information

Funding organisations of community-based programs would also benefit from using networks. Such networks, adhering to these same seven 'C' qualities, can help to reduce the complexity of demands for information from community-based programs by streamlining information requirements to make them more consistent across funders.

Principle 7: Adopt ethical practices in conducting monitoring activities

Any program that collects and records information about people must do so respectfully and according to ethical principles.

The ethical principles of the MM&M are:

- Stakeholders, in particular people with disabilities and their families, are involved and have a strong voice in relation to the collection, use and dissemination of information.
- Only personal information that advances outcomes for people is collected.
- People providing personal information are told why it is needed. They should be given the choice to provide information or not. They have access to it, and can check and use the information. Supported decision making may be needed for some people, to help them decide if they want to participate in monitoring, or allow their data to be used.
- People providing personal information *own* that information. The information is only used with their permission, and they are informed about how it will be used. Personal information will be protected within the bounds of local law.
- In all collection processes, privacy is protected; where it is published or made public, information will be presented in a way that protects the anonymity of individuals.
- Data can be shared with other organisations only with the permission of the person. Sometimes this may seem to conflict with the principle of collecting information only once (Principle 4), but the decision is up to the person.
- Information should not be used in a way that discriminates against or unfairly disadvantages anybody.

- Think about how information is stored and who has access to it. Only those who need it and will be careful with it should have access.

Protecting the privacy of program participants

When talking with the program participant and their family to collect personal information, it is important for the person collecting the information to consider the location and who else is close by. If other people can see and hear the conversation and it is not private, then ask the participant and family whether they would like to move to a private place or would like you to ask others to move away so they cannot hear your conversation.

DECIDING TO USE THE MM&M

Why is monitoring important?

Monitoring supports the development and sustainability of community-based programs. Community-based programs need robust tools and resources like the MM&M to undertake and sustain monitoring activities (WHO et al 2010).

Monitoring provides information that can be used to:

- ✓ reflect on how the program is going and make adjustments as needed
- ✓ document and report on progress and outcomes for participants and the organisation
- ✓ track service quality
- ✓ learn from what has worked well and what has not, and identify aspects of the program that need to be modified or improved
- ✓ monitor inclusion in mainstream services
- ✓ help identify unmet need for participants, families and communities
- ✓ support fundraising strategies
- ✓ inform evaluation and monitoring of the CRPD
- ✓ share learning on activities that have led to positive change
- ✓ inform policy development at local, national, or even international levels
- ✓ make comparisons across programs within a country, or between countries
- ✓ identify and describe good practice.

Example: Using information for decision making (Solomon Islands)

The CBR principles of equality of opportunity, accessibility and participation and inclusion in society were influences on the Solomon Islands Department of Education which led them to adopt an inclusive education policy. The Department set up an inclusive education working committee. The national CBR program is involved. The CBR program provided information to the working committee on the number of children with disability in the villages where they had field workers. The government was given information on where the children lived, their age and disability and whether the child attended school. This information helped the Department of Education to justify setting up a National Learning Support Resource Centre. The Centre provides talking books,

toys, equipment and other resources to support the teachers in mainstream schools to include children with disabilities. Information about the Centre and the resources was provided to teachers; schools where there were children that were not attending school were particularly targeted.

Who can use the MM&M?

A wide range of programs with diverse stakeholder interests, priorities, and information needs can use the MM&M. It is relevant to program managers, funders and service users, including individual participants, their families and communities, as well as government bodies and related services.

Example: CBR stakeholders (Timor Leste)

The core business of the CBR program in Timor-Leste, implemented by the NGO Klibur Domin, is health, education, livelihood, social, and empowerment. The program supports people with disabilities, particularly children in their communities. A mobile rehabilitation team identifies children with disabilities in the villages. Children receive medical treatment, physiotherapy and occupational therapy from the mobile team whilst living at home, or stay at the St Damien's respite Centre at Klibur Domin for a few weeks for more intensive treatment. The CBR program also supports the children with wheelchairs, ramps and other equipment for home and so many now attend school for the first time.

The key stakeholders for CBR in Timor-Leste are:

- The DPO and their members and families
- Funders, including the Australian Government (DFAT formerly AusAID), Handicap International and Enablement from the Netherlands
- Community organisations and networks
    - Other NGOs and CBR programs that also may provide special support for the children e.g. East Timor Blind Union (ETBU).
    - The local school teachers and principals
    - Government including the Ministry of Social Solidarity, Ministry of Education, Ministry of Health, Secretary of State for Training and Employment, National University of Timor-Leste
    - Community volunteers
    - Local leaders from national, district and village.

How can the MM&M help my program?

The MM&M is designed specifically to assist programs to plan, design and implement monitoring activities, with an emphasis on local control and stakeholder involvement. It is structured so that monitoring can start small and simply. The program can start with a few information items and then gradually build up over time and expand to include more information as capacity allows.

Monitoring your program can help it to develop, grow and be recognised as a positive force for people with disabilities.

Monitoring activities can produce information on

- Numbers of program participants and what services were most used
- Activities and participation of the person with disability in different life areas
- Attitude of the family
- Relationships and supports
- Services and policy
- Training undertaken by volunteers
- Changes in the village and local community (e.g. more inclusive employment practices)

Program monitoring information should be linked to the goals of the program and the program's activities, so that it is possible to detect relevant changes in the things that the program is aiming to affect or change. The MM&M can also help programs capture information about less obvious changes and outcomes.

Example: Using information to improve understanding of program outcomes

An assessment shows that a child with a disability lives in a house with three steps. The child needs a ramp to independently get outside their home to go to school. The community program arranges for a ramp to be built to replace the three steps. The program might already record that they have provided a ramp to a child. However, there are other changes that occur that could also be recorded:

- How often the child goes to school;
- How often the child joins in community activities, e.g., playing with friends;
- Whether there are jobs the child now assists with around the home e.g., feeding the chickens;
- Whether other family members benefit from the ramp, e.g., instead of carrying bags of rice into the house, the parent now uses a trolley;
- Whether the parent is able to work outside the home because the child now goes to school;
- Whether the program workforce has benefited, e.g., the community worker knows more about what works with ramps - the ramp surface, direction and how steep.

The MM&M can be used in different program and country contexts because its structure accommodates the diversity and complexity of programs, and disability experience in different environments.

Example: Using monitoring information for service development (Lao-PDR)

An NGO in Lao-PDR, Co-operative of Orthotics and Prosthetics Enterprise (COPE), was expanding their service into two new regional areas. COPE provides assessment and treatment for a person who has a leg or arm amputation, club foot or equinus. They organised consultation workshops and training for key stakeholders in each region. Health centre staff attended, including representatives from remote health centres. COPE staff explained their services, the financial support available for a person to attend and the assistance provided. Each village chief was to collect information on the people who may benefit from COPE services by completing a survey form. The health centre staff had the responsibility to train the village chief on how to record the information. In one region, the forms from the village chiefs indicated that there were up to 100 people who could benefit from COPE services. In the second region the survey completed showed 80 people needed COPE's services. After extensive planning, special assessment clinics were scheduled and set up in each region. As it turned out, less people (30) people from the first region and more people in the second region (118) had the health conditions. People with other health conditions turned up to the assessment, and COPE referred these people to other services. It was difficult to schedule services and resource the assessment and training services appropriately without more accurate information on the number of people in need.

COPE recognised that there was a problem with recording the information. The village chiefs had difficulty understanding the survey form as well as recognising the health conditions. The inaccuracy in recording was a problem for COPE for their planning and budgeting for services. COPE designed a new survey form to use pictures rather than words. The new form had boxes with pictures of different people (identity masked) with each of the health conditions. Written beside each picture was the name of the health condition and a number to tick. The new form means COPE can be more confident in the accuracy of their survey and better plan for services. The success of the new survey form means that COPE is now extended their survey information to record information on barriers for people who have been assessed, but not attended their follow up appointments.

USING THE MM&M

The steps described in this section (and illustrated in Figure 2) are:

Before you begin: First decide whether you want and need to undertake new monitoring activities and why

Step 1. Prepare for collaboration: Prepare for collaboration with stakeholders to design the monitoring activities and develop a plan

Step 2. Design information:

- Undertake your stakeholder workshop/s and carry out five exercises to design your monitoring activities

Step 3. Develop a monitoring plan

- Develop your program's monitoring plan
- Check and pilot test your monitoring activities and monitoring plan

Step 4. Undertake monitoring activities

- Train the people to do the monitoring activities
- Put the plan into action – start the monitoring activities and collect the information

Step 5. Analyse and use information: Collate, analyse and use the monitoring information

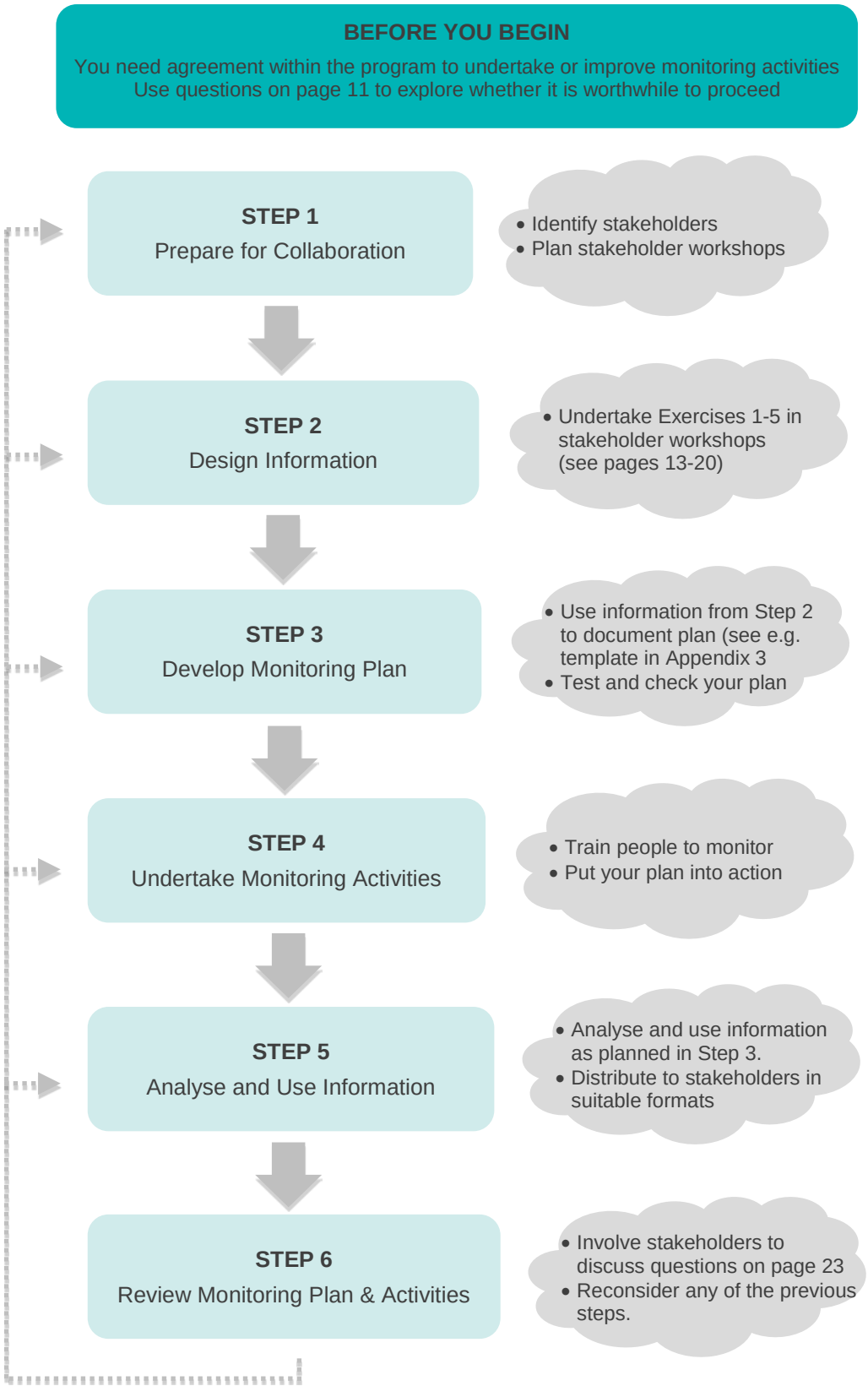
Step 6. Review monitoring plan and activities: Review progress with monitoring activities and, if necessary, revise.

Remember the Principles of the MM&M

Principle 1: Monitoring is locally owned and controlled by the program
Principle 2: Monitoring is participatory and inclusive
Principle 3: Monitoring information is used for the benefit of stakeholders
Principle 4: Information that does not change should be collected only once
Principle 5: Monitoring is easy and part of everyday routine
Principle 6: Use networks to sustain and build capacity for monitoring activities
Principle 7: Adopt ethical practices in conducting monitoring activities

Figure 1: Flowchart of MM&M process:

Steps in the process of designing information and planning and implementing monitoring activities



Before you begin

Most programs already collect some information on their participants, services, and workforce. It may be possible to build on the information and processes already in place in your program. However, it is good to take a fresh look and use a systematic approach.

This first step is about deciding whether you want and need to undertake new monitoring activities or review your current monitoring activities. Program managers and key stakeholders might ask themselves some general questions to help make this decision.

Questions program managers and key stakeholders might ask

- What information do we currently collect that tells us about the way our program can influence the lives of people with disabilities?
- Are there gaps in our information? Do we need to know more?
- Is the information we collect now useful? Do we need to keep collecting all the information we currently collect?
- If we have more or different information, how might it help us? What change might we aim to bring about and how might information be useful for this?
- Do we need to provide more information about what is happening for people with disabilities to influence the decisions made by our policy makers more effectively?
- Do we have the capacity to collect more information than we do now?

There needs to be general agreement within the program that improvements are needed to current monitoring activities. Planning and carrying out monitoring takes time and resources; for example there is a cost for training, and collecting information takes time. It is important to consider costs when planning, and to absorb monitoring in usual activities, where possible, to reduce these costs. However, monitoring done well is worthwhile for all stakeholders. Monitoring your program can help it to develop, grow and be recognised for the work you do and the support you provide for people with disabilities.

Your program should reflect on **why** there is a need to monitor and collect information, and how the information could be used. Discussing this with stakeholders will help you decide whether you have gaps in information and whether you wish to improve it.

➢ ***At the end of Step 1,*** *you should have decided whether to proceed with the next steps.*

How your monitoring information might be used

- Measuring progress and outcomes for participants and families, e.g., participation in education or training, to see if the program is achieving its goals
- Providing your social welfare department with information about how many people have been supported with microfinance to set up their own small business
- Reviewing the program's activities, e.g., the increase in the number of self help groups started in the last 3 years
- Providing information to interested parties to encourage them to support the

program, e.g., telling a mining company how many participants have been trained in welding through the program
- Promoting the program by providing the media with a personal story about the successes of a person with disability
- Providing reports to the DPO and provincial leaders on the number of volunteers involved with the program
- Accounting to funders or DPOs for outcomes
- Showing decision-makers how simple activities can produce useful and beneficial information, to get their financial support and include monitoring in future plans

Step 1: Prepare for collaboration

The next step is to prepare for the collaborative workshops needed to design monitoring activities and develop a plan. This process should involve a range of stakeholders to make sure the information collected meets their needs. When stakeholders have been involved it is more likely that the information collected will be good quality, and monitoring activities will be sustained.

Who should be involved in the stakeholder workshops?

Aim for broad representation, but not too many people. Different groups might be:

- Participants in the program or their representatives
- DPOs
- Program workforce
- Funders
- Other community groups
- Village leaders
- NGOs

Decide who from these groups might be appropriate for you to involve. Try to engage people who know the program, are interested in it, and represent the stakeholders, or can represent more than one group of stakeholders.

It is important to plan the workshops or discussion groups carefully. Make a list of the topics to cover. Decide who will lead the discussion, and who will record what is discussed and agreed. Think about what equipment and resources you will need, for example, large pieces of paper, pens, and a chalkboard or white board to write up what the group agrees on. Think about how long the workshops should be. If your workshop is going to run for several hours make sure there are breaks. Some workshops might involve several shorter discussions over two or three days. Smaller, less formal discussions might work better for some stakeholders. The approach you take should be tailored to your situation, your organisation, and your stakeholders. Remember Principle 2 especially, and plan to ensure the workshops are participatory and inclusive.

Example: Using information to lobby for change (Fiji)

The coins and notes in Fiji were different colours but not different sizes and textures. People who are totally blind or who have severe low vision could not tell them apart. In the late 90's, the DPO United Blind Persons of Fiji (UBPF) and the Fiji Society for the Blind (FSB) worked together and used information to lobby to the Governor of the Reserve Bank of Fiji (RBF) through their currency committee to have the design of Fijian currency changed. They used information on the membership of the DPO and the Society and also on the concerns raised by members at annual meetings. The Society's CBR field workers referred people to the DPO if they experienced difficulty with the coins and notes. The DPO and Society collected information from these case studies about the challenges for persons with vision impairment, and the outcomes including how taxi drivers or family members or shop owners cheated them. The monitoring information on the person's environmental factors and barriers such as attitudes, on the outcomes and the numbers of people who are totally blind was gathered. The DPO used this information in a report to support their lobbying at meetings with the RBF's currency committee. The DPO continued to take the lead role in advocating to RBF through meetings. There were some challenges that the DPO encountered, however in 2007 Fiji issued new designs for their notes with different sizes. In the following years there have been similar changes to size and texture with Fiji's coins.

Step 2: Design information

This step involves undertaking five exercises, in your stakeholder workshops, to design monitoring information and activities.

In the workshops there should be an introduction to explain briefly the purpose of the workshop, what will be covered, and what the goals are. In particular, the value of monitoring could be outlined at the start, as well as the importance of information design.

Use the following 5 exercises to work through the information design process. The exercises might be done as one group or, for some exercises, participants can divide into smaller groups and report back to the full group at the end of each exercise.

EXERCISE 1: Why is information needed? How will it be used?

Examples of questions to discuss with your stakeholders:

- What questions would you like to be able to answer about the program?
- What statements would you like to be able to make in 12 months time about progress? How will you use the statements e.g. to whom?
- What are DPOs most concerned about?
- What do policy makers want to know? What are their current priorities and concerns and how do these relate to the program?
- What do they think is 'success'? What costs are they worried about?
- How do your activities relate to the articles of the UNCRPD (UN 2006)? Do you want to be able to point to outcomes you have achieved that relate to these articles?

- What are the high priority reporting requirements of funders? Do you want to negotiate with them (or educate them) about their/your requirements?
- Who are the other stakeholders and champions (the people who might advocate for, and help your community based program) and what might they want to know?
- Once the information is collected, what will you do with it and who will use the information?

Refer to 'why monitoring is important' (p. 5) for examples of the reasons for monitoring.

➢ ***At the end of Exercise 1,*** *you should have a summary of why information is needed and what it will be used for, plus a list of 'key questions'* stakeholders want to answer.

Examples of key questions you might want information about, and why

- What progress has the program made with communication and self-care (for example)?
- What supports has the participant's family now received? What has this cost? What difference have they made?
- What are the outcomes of the program's school support activities? Are different stakeholders interested in different outcomes?
- Are we achieving better links with mainstream services? Is this improving access for people with disabilities?
- Are people with disabilities (our participants and others in the community) more involved and participating in the community?
- What are the outcomes for the families of people with disabilities? Are different stakeholders interested in different outcomes?

EXERCISE 2: <u>What</u> items of information are needed?

In this exercise, the group identifies relevant information items in the Menu. For each of the 'key questions' identified in Exercise 1, think about:

- What information items will help answer the question? List all relevant items.
- Which items provide the main information needed? Identify the essential items.

The discussion might be done in small groups with each group taking one question from Exercise 1. The group should discuss and agree what Menu items are needed to answer their question.

Some programs may need to balance the information they need against the resources needed to collect it. Collecting a few pieces of important information and doing this regularly and accurately is better than spending time collecting incorrect information, or information that is not used. Trying to collect a lot of information might put too much pressure on staff, so that the information is not collected well or consistently. Decide what your top priorities are, remembering that monitoring activities can be expanded over time.

➢ ***Don't try to collect all the items in the Menu, only those items that answer your 'key questions'***

Three 'key question' examples and possible information items from the Menu are in Table 1.

Table 1: Example 'key questions' and possible information items from the Menu

Example 'key question'	Possible information item/s
What progress with communication has the program participant made? The reason for asking this question may be that the program has introduced a new method for improving communication, but it takes a lot of staff time, so the program wants to know if the new method achieves good outcomes for participants.	**P2 Person – Functioning and Disability** **P2.2 Activities and participation Communication (domain 3).** Other domains to consider are: Interpersonal relationships (domain 7), Education and Employment (domain 8).
What supports do the participant's family receive? The reason for asking this question may be to compare what the family is receiving compared to their identified needs when they entered the program.	**A1.2: Activities targeting people and families**, e.g. • Counselling – social or supportive counselling • Therapy – home exercise programs
What are the outcomes of the school support activities provided by the program? The reason for asking this question may be that the program needs to include information on service effectiveness in a report to a funder.	**A1.3: Activities targeting the community**, **Improving access to mainstream services**, e.g. • Promoting inclusion in mainstream schools • *You may wish to add locally designed items on the school support activities the program is doing* **A2 Activities – Activity Outcomes** Select which outcome items and examples are most relevant, e.g. • What did the activities accomplish? (e.g. parental pride in child's achievements; reduced stigma) • Other locally developed items related to the goals of the supports provided Information relevant to outcomes can also be provided using 'Person' items, e.g. **P1.13 Education** (current educational participation). If recorded for each child, add across all participants to find how many attend school.

➢ ***At the end of Exercise 2,*** *you should have a list of all the identified information items from the Menu to answer your 'key questions'. It may be useful to group the items you have identified into 'person', 'organisation', 'activities' and 'workforce' (as outlined in the Menu). Some items might help to answer more than one question.*

Example: Redesigning information for monitoring (Papua New Guinea)

A NGO in Papua New Guinea was redesigning a registration form for people with disabilities participating in their organisation. They used ideas from an early version of the Monitoring Menu to create a new draft form. The University of Sydney team was asked to comment. The NGO made further changes, and adapted some items to suit their local community and environment.

The resulting form contained:

- items designed locally, e.g., information about guardianship arrangements
- items on the need for help with activities; the list of activities was selected from the ICF (now in the Menu)
- precise language (e.g., talking about impairment of parts of the body, rather than disability in parts of the body)
- a new question about the person's interests and goals.

EXERCISE 3: How will we collect and record the information?

This exercise involves thinking through how the information should be collected and recorded. Principle 5 is especially important here – to keep monitoring simple, so that it is easy and part of everyday activities. The Menu has a recording guide for each information item, so that is also a good place to start, although for some items you might decide to develop your own way of recording the information.

For each Menu item identified in Exercise 2 answer the following:

- Is this information already collected? If so, can we build on or modify what we already collect so it is more reliable or fit for purpose?
- If the information is not already collected, how should it be recorded (e.g., in words or pictures; using scores; using tick-box categories)?
- Think ahead to how the information will be compiled and analysed (Exercise 5). How might this affect the format of the records? Are computers available and would they be useful?

Refer to Table 2 to see examples of how information might be recorded for different items.

Table 2: Possible recording methods for 'key questions' and menu items from Table 1.

Example 'key questions' and menu items	Possible recording method
What progress with communication has the program participant made? P2.2 Activities and participation, Communication (domain 3).	Record in routine visits or meetings, involving CBR worker, family and child. Observe change over time. Record 'difficulty with communication' or 'assistance needed with communication' (see Menu for details of how to do this) *Note*: The Menu offers two other scales for recording this item: *Participation restriction; Satisfaction with participation*. It could be useful to ask the child about their satisfaction and how they feel about participating in communication.
What supports do the participant's family receive? A1.2: Activities targeting people and families	The DPO representative might record information about what support is being received each time they visit the family (e.g., by taking brief notes that are then kept in the participant's file). You can also use the options listed in the Menu to tick a box (e.g. 'financial aid' or 'therapy'). Or you can add your own categories to summarise the type of support provided.
What are the outcomes of the school support activities provided by the program? A1.3: Activities targeting the community Improving access to mainstream services: e.g.: • Promoting inclusion in mainstream, schools • Possible additional locally designed item on the program's school support activities A2 Activities – Activity outcomes Select which outcome items and examples are most relevant, e.g.: • What did the activities accomplish e.g. Parental pride in child's	Information for A1.3 can be recorded by ticking options for the types of supports the program offers for schools and students (e.g. teaching school staff basic rehabilitation techniques). These are in the Menu and can be expanded to list more options relevant to the program. Information for A2 'What did the activities accomplish?' Child/participant more confident in participating in mainstream services and activities. Information can be obtained in various ways. Regular discussions with the parent/child will discover this information and it can be recorded and updated. Information for P1.13 'Current educational participation' could be recorded simply to

achievements, reduced stigma • Other locally developed items related to the goals of the supports provided P1.13 Education (current educational participation): If recorded for each child add across all participants to find how many attend school	indicate whether the child is attending school or not. This information might be obtained from school records and meetings, or by asking the family and child. Outcomes for the program can then be indicated by summarising information for items P1.13 across all program participants, and tracking this over time. See also 'recording guide' for all these items in the Menu

➢ ***At the end of Exercise 3*** *you should have identified, for each Menu item from Exercise 2, how the information will be recorded.*

EXERCISE 4: When and where will information be collected, who will collect it, and how will it be stored?

In this exercise, the group decides on the practicalities of collecting information. For each Menu item, discuss:

- **When** should the information be collected?
  - At intake, to indicate a starting point?
  - At key times, to monitor progress or outcomes?
- **Where** is it possible and convenient to collect the information?
  - At the participant's home? At the centre? At a school or workplace?
  - Does this affect how the information is recorded e.g. on paper, computer?
- **Who** is able to collect it and who has the relevant skills? Who should be involved in providing information? What training might people need to collect information (see also Step 3, on planning).

For some Menu items different stakeholders may have different perspectives. For example, the person with disability, a family member, and a community worker may have different perspectives on the person's activities. Think about whose perspective should be recorded to answer the 'key questions' to which the information item relates. Sometimes you need to record more than one perspective.

This exercise requires thinking about all available resources and how they can be used. Look for other potential ways to collect monitoring information and think beyond the community based program and the workforce. Other people and resources that a program might use to support the collection of monitoring information include:

- A family member who lives in a different house, but in the same village
- Local health care worker
- Village chief or elder
- Teacher
- Youth group or local youth volunteers
- Women's Union

- DPO
- Cluster development committee/team
- Religious leader
- Other NGOs
- Government representative(s).

Using the example recording methods from Table 2, people involved in collecting information might be:

- Both the mother and the school teacher, who record their perspective on the participant's difficulty with communication (spoken messages)
- The DPO representative, who provides information on supports received at each date that they visited the family
- The school principal, who provides the information once per year, about the children with disabilities who attend the school.

Another important question is whether information should be collected and/or stored on paper or on computer. This will depend on what resources the organisation and staff have available, and may be influenced by how you plan to use the information. Think about who should have access to the information. Only those who need it and will be careful with it should have access. There must be a way of keeping confidential information secure (see Principle 7).

➢ ***At the end of exercise 4*** *you should have identified, for each Menu item from Exercise 2, who will collect the information, where and when they will collect it. You should also have decided how monitoring information will be collected, recorded and stored.*

EXERCISE 5: Who will use the information and how?

In this final exercise, the group considers the use of the information by answering questions such as:

- Who will use the information and in what ways?
- Who might be affected by the information and in what ways?
- How will the information be compiled?
- If different perspectives of different stakeholders are to be recorded, how will they be combined for analysis?
- Who might have an interest in providing inaccurate information for personal reasons e.g. someone collecting information might record that a piece of equipment was provided when it was not.
- How and when will different stakeholders want to obtain information? For example do they mainly use radio, newspaper, newsletters, word of mouth, text messages on phones?

Some of your answers to the questions in Exercise 1 may provide a good starting point for this discussion.

➢ ***At the end of Exercise 5*** *you should have a list of all the main information users, together with what information should be provided to them, for what purposes and in what form (e.g. summary report, individual participant information)*.

Step 3: Develop the monitoring plan

Documenting a monitoring plan will ensure that you keep a record of all the discussions you have held and the agreements you have reached. The products from the workshop exercise will provide a great deal of the guidance you need in planning. You now know:

- What information you will collect to monitor the program
- What Menu items you will use to collect this information
- How you will record the information
- How often or regularly you will record this information
- Who will collect the information, where and when they will collect it, and how it will be securely stored
- How stakeholders will use the information.

It is important to document all these agreements and intentions. These form the first part of your monitoring plan. The next part of the plan will describe:

- The steps that you decide to take to make monitoring happen
- The people who will carry them out.

It is best if you develop your own format for planning. The matters and actions you need to consider and plan include:

- How monitoring will fit in with day-to-day processes
- Who will be responsible for what
- What you need to put in place so that information can be recorded: designing forms and computer databases requires time and resources. Literacy levels of people collecting information should be considered, e.g., possible use of visual images (e.g., pictures, smiley face), ticks, crosses, etc.
- Resources: Time and equipment need to be planned e.g. whether new computer systems will be needed.
- Training of all the people who will be involved. What skills do different people need and how can they be supported? What preparation do they need e.g. basic tips on how to interview and communicate with people with all kinds of disabilities; how they obtain consent, how they share information and provide feedback, how they understand their responsibilities (e.g. Principle 7 on privacy).
- Dates for pilot testing and implementing the monitoring activities – consider ‘staging’ or introducing monitoring processes gradually
- How information will be disseminated – via reports, media (radio, newspaper etc), via stakeholder seminars; who will analyse the information
- A timetable for all these actions to achieve an operating monitoring system.

Having an overall plan will help avoid starting ‘too big’ – you get a view of the work and resources required all the way through. You may decide to revise the plan to make it more

feasible to achieve. The plan may help you decide that you need to advocate for more resources to be able to collect important information.

While all community-based programs are different, there are some general management approaches appropriate to planning e.g. thinking about resources, what people are responsible for, procedures for documentation, pilot testing, analysing, and reporting. You can refer to general management resources or sector-specific resources (refer to the Resources section for links).

Included in Appendix 3 (p. 32) is an example template developed by our collaborators on the MM&M project. You may wish to adapt it to your purposes.

Check and pilot test your monitoring plan

Before you start the monitoring activities it is important that you pilot test them. For example, if you want staff to record a person's age or goals:

- Ask staff to comment on draft forms or recording methods
- Ask them to test draft questions with real people and give these people a chance to comment on the questions and the process. Ensure you include a representative sample of people with different communication abilities; this will ensure you are aware of preparation needed and any adaptation needed.
- Check all the later actions needed. How will records be kept? How will they be retrieved when they are wanted? How can they be used in reports?
- Then use the information you obtain from your testing to review and refine your monitoring plan.

Step 4: Undertake monitoring activities

Now that you have your plan in place you are can carry it out and start monitoring.
As you monitor, keep an eye on the process and be ready to revise the components of the plan as you go. For example:

- Do staff and other stakeholders need more training?
- Are more resources and materials needed?
- Do participants and family have some information provided to them about their progress soon after they begin with the program, so they see the value of monitoring?
- Can some (anonymous) information be provided to decision-making or policy stakeholders to show the benefit of monitoring and encourage their support of the monitoring plan?

Example: Monitoring the outcomes of a training program for DPO members (Philippines)

Students from the University of Philippines and CBR field staff worked closely with the DPO and gathered information about their needs during their regular meetings together. One of the needs raised by the DPO was the need for their members to learn how to measure a person's blood pressure using a blood pressure monitor

(sphygmomanometer and stethoscope). Often the community health workers are not available on the weekends. This was a problem for elderly people and those who had a stroke, who needed help on the weekends to have their blood pressure monitored and prevent secondary disabilities from developing. The DPO members wanted to learn how to measure blood pressure. The training program was designed to teach the skill. A checklist was used to teach the procedure and also as a sort of exam to monitor their skill. The same checklist was used in spot checks to assess their skills after one month. The information from the exam and spot checklists was used to monitor the outcomes of the training program.

Step 5: Analyse and use information

It is really important to use the information, as planned, and probably also in additional ways that you think of, as your information becomes used, understood and valued. As information becomes available, people will want to see and use it.

Go back to the 'key questions' and related important information that stakeholder discussions agreed on (in Exercises 1 and 5). Provide this information back to stakeholders in formats they will appreciate – verbal feedback, short written reports and notes, radio interviews, newspaper articles, community forums etc.

You could hold further stakeholder discussions to talk about the information and see what people think about it and what they use it for. What else could it be used for? What actions will you and they take based on the information? How can the information be used for advocacy? How can the information be used to develop or change programs? Does the information give you ideas for research projects? Do you have research partners who may be able to use it?

Example: Using information from parent interviews to adapt an urban program to a rural setting (Vietnam)

A successful early intervention and education program for children with intellectual disabilities has been operating in Hue, Vietnam by the Office of Genetic Counseling and Disabled Children (OGCDC) for a number of years. Many of the children have progressed in school, are independent in self care and help around home. The team aimed to set up a similar program in a rural mountain area within the province. Initial contact and appointments were made with the parents of children identified to have an intellectual disability. However, parents appeared unwilling to cooperate and sometimes refused to allow the children join the program.

The team needed to find out what the barriers. The team devised a small number of prompt questions, discussion points and how to record the answers. Program managers interviewed some of the parents. Many of the parents did not see the value of early intervention nor consider their child's potential contribution to the household. They needed to leave their farm, lost income, time and energy if they travelled the distance and took their child to the appointment. A short report was developed which combined

the parent interview responses and showed that the key barrier was the parent's attitude towards intellectual disability. The report helped the team to seek funding for the release of staff members to conduct awareness training for the parents, other family and community members. The awareness program targeted attitudes and used examples of children (not identified) from the Hue program. They described the early intervention program and the child's progress and achievements. The team adapted their model of operating to involve home visiting rather than centre based appointments to minimise the parent's time away from their work. The home visitor to child ratio is higher in the mountains (1:5 compared to 1:3 in Hue). However, there is now increased parent participation and results with the children's progress. The information recorded has justified the additional activities and staff time from the team.

Step 6: Review monitoring activities & the monitoring plan

A review process can help you improve your monitoring activities and monitoring plan. The review should involve all those who have been involved in the process so far – in designing the information, carrying out the monitoring activities, and using the information. The review could consider questions such as:

- What does summarised monitoring information look like? Is information being provided to stakeholders as planned? Is it being used? Is it valuable to the stakeholders who wanted it? What do stakeholders say about this?
- What has worked well, and what has not worked well? How could the activities be improved?
- How do program participants and their families view the monitoring process and the information gained? Do they have suggestions for improvement?
- How well have monitoring activities been sustained? Are they carried out as well as they were at the beginning? If not, is there a problem with resources, commitment, or something else?

Refer again to Exercises 1 and 5 (p. 13 and p. 19) to see if you are achieving what you hoped at the start. Based on the information from this review you may decide to improve your monitoring activities, e.g., by changing what information is collected, or how it is collected, used or reported.

Some examples of monitoring questions and information items from the Menu, as they relate to the CBR Matrix and cross-cutting themes such as community and participation, are provided in a table in Appendix 4 (p. 34). You may find it useful to refer to this during your review.

DEFINITIONS AND TERMS

Stakeholders: 'Stakeholders' includes anyone interested in the success of the program. The most important stakeholders are the people with disabilities (participants) and their family – the people whom the program aims to serve. Other stakeholders are Disabled Persons' Organisations (DPOs), other community groups, advocacy groups (e.g., those that support people with disabilities), community leaders, the organisation responsible for the program and its workforce (volunteers and staff), funders, and other local and regional organisations that work with, or could work with the program (for example women's and youth groups).

Disabled Persons' Organisation (DPO): An organisation that is majority run and controlled by people with disabilities. The focus is on the situation of people with disabilities. The role of the organisation varies but may include: implementation and monitoring of human rights, identifying need, providing a voice, advocating change, public awareness, evaluating services, and providing a vehicle for self-development.

Participant: The main beneficiary of the program activities. It may be an individual, the person with a disability, the family, the village community, or all of these.

Family: Relatives and members of the family of the person with a disability.

Non-governmental Organisation (NGO): NGOs are legally constituted, usually not-for-profit corporations through which community-based programs are often funded and/or supported.

Funder: An entity that provides economic support for a community-based program. Funders are usually identified financial partners to whom the program is accountable for the expenditure of money and the achievement of contracted outcomes.

Information item: A clearly specified topic or concept about which information is to be collected. An information item 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.

***Disability: WHO definition*:**
Functioning is an umbrella term encompassing all body functions, activities and participation; similarly, **disability** serves as an umbrella term for impairments, activity limitations or participation restrictions (WHO 2001, page 3). Disability is … the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives (WHO 2001, page 17; see also WHO 2013).

Disability: UN Convention purpose and inclusion statement (*Article 1****)***:
The purpose of the present Convention is to promote, protect and ensure the full and equal

enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

RESOURCES AND REFERENCES

CBM (2012) Inclusion made easy: A quick program guide to disability in development. Available from: http://www.cbm.org/Inclusion-Made-Easy-329091.php

Handicap International (2014). Making it work: A Guideline for good practices for inclusive development. Available from: http://www.makingitwork-crpd.org/tools-and-guidance/guideline/

International Disability and Development Consortium (IDDC) Make Development Inclusive: How to include the perspectives of persons with disabilties in the project cycle management guidelines of the EC. Available from http://www.make-development-inclusive.org/tools.php?spk=en

International Fund for Agricultural Development (IFAD) (2002). Community-driven development decision tools for rural development programmes. Available from: http://www.ifad.org/english/cdd/pub/decisiontools.pdf

Kaplan, A. (1999) Development Dossier: The Development of Capacity. Retrieved 13 March 2014 from http://www.un-ngls.org/orf/documents/publications.en/develop.dossier/dd.05/dc.contents.htm

Lukersmith, S., Hartley, S., Kuipers, P., Madden, R., Llewellyn, G., Dune, T. (2013) Community-based rehabilitation monitoring and evaluation methods and tools: A literature review. *Disability & Rehabilitation*. Early on-line 1-13. DOI: 10.3109/09638288.2013.770078

Madden R, Glozier N, Mpofu E, Llewellyn G 2012. Health, functioning and disability: how common language and data can enhance policy making. In *Commonwealth Health Partnerships 2012:126-129*. Commonwealth Secretariat, London, UK.

Madden RH. Dune T. Lukersmith S. Hartley S. Kuipers P. Gargett A. Llewellyn G (2013a). The relevance of the International Classification of Functioning, Disability and Health (ICF) in monitoring and evaluating Community-based Rehabilitation (CBR). *Disability & Rehabilitation*. Early Online:1-12. DOI: 10.3109/09638288.2013.821182

Madden RH, Fortune N, Cheeseman D, Mpofu E, Bundy A (2013b). Fundamental questions before recording or measuring functioning and disability. *Disability & Rehabilitation*; 35(13): 1092–1096

Participatory Rapid Appraisal for Community Development: A training manual based on experiences in the Middle East and North Africa (1991). Institute for Environment and Development. Available from: http://pubs.iied.org/8282IIED.html?k=participatory rapid appraisal for community development

TAI Human Research Inc. ICF illustration library. Retrieved 12 March 2014 on http://www.icfillustration.com/top_e.html

United Nations (UN) (2006). Convention on the Rights of Persons with Disabilities. Available from: http://www.un.org/disabilities/convention/conventionfull.shtml

World Health Organization (WHO). The International Classification of Functioning, Disability and Health, 2001; Geneva, WHO. http://www.who.int/classifications/icf/en/ and http://apps.who.int/classifications/icfbrowser/

World Health Organization (WHO), UNESCO, International Labour Organisation (ILO), & International Disability Development Consortium. (2010). Community-Based Rehabilitation (CBR) Guidelines. Geneva, Switzerland. Available from: http://www.who.int/disabilities/cbr/guidelines/en/

World Health Organization (WHO), International Labour Office (ILO), and UNESCO, *CBR. A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities*, 2004: Geneva. Available from http://www.who.int/disabilities/publications/cbr/en/

World Health Organization (WHO) and World Bank. *World Report on Disability.* 2011, WHO: Geneva, Switzerland. Available from http://www.who.int/disabilities/world_report/2011/report/en/

World Health Organization (WHO). How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). Exposure draft for comment. October 2013. Geneva: WHO. Available on http://www.who.int/classifications/icf/en/

World Health Organization (WHO). *Global Disability Action Plan 2014-2021*. Retrieved on 9 February 2014 from http://who.int/disabilities/actionplan/en/index.html

APPENDICES

Appendix 1: What is the difference between monitoring and evaluation?

Monitoring and evaluation are not the same. Monitoring is ongoing and is used to look at changes and progress. If done well, information collected through monitoring is used for evaluation. Evaluation is a method of making a judgment on the merit or significance of a program, service or activity. It involves assessment of performance against a set of standards or benchmarks. Some of the differences between monitoring and evaluation are shown in the table below (adapted from Lukersmith et al 2013).

	Monitoring	Evaluation
Perspective	Internal element Confirming program activities and participant experiences related to goals Usually at program, local community or regional level (individual participant, family and local community)	External element Investigative or research oriented Can be broader or more general than the program (e.g. national, systems or policy level)
Frequency	Ongoing/regular	'One off' or occasional
Who performs it	Information/tool used by program stakeholders e.g. staff, participants	Process conducted by or includes others external to the program e.g. researchers
Goal	• identify and check for changes (program) • objectively confirm and validate status or progress • accounting for use of resources • empowering • identify and share best practice	• outcomes • impact – were the goals achieved? • identify positive and negative aspects • use for another purpose (e.g. improvement to future work)
Outcome	• potential to identify problems • help to identify additional goals • empowering	• win support or make changes that are needed

Appendix 2: Outline of method for MM&M development

Rationale: The motivation for developing a monitoring toolkit for CBR and similar programs arose from the recognition of two key factors:

- The current state of development of the field: CBR is a valued community development approach but there is a lack of evidence of its efficacy (World Report and more recently confirmed in the Global Disability Action Plan) (WHO 2011; 2014);
- The appropriate method: To build evidence about CBR, consistent with the philosophy of CBR and disability inclusive development, the starting point should be to encourage monitoring – locally controlled and owned, and empowering stakeholders with information (see Appendix 1for the key differences between monitoring and evaluation). Monitoring is an essential first step to improve the quality of information and understanding of these programs, and to review and plan program priorities and goals. Locally controlled monitoring is more likely to be sustainable over the longer term.

Method: Two complementary components of the method have characterised the research and development over three years (2011-14) leading to the prototype MM&M: collaborative and participatory research with CBR program stakeholders and international collaborations, informed by review and analysis of relevant literature.

Reviews of the literature were commenced early in the project. A search for literature on monitoring and evaluation of CBR yielded 36 articles meeting search criteria. These 36 articles were analysed in two ways:

- The first analysis looked at the methods for monitoring and evaluation. It was found that there were a variety of tools and methods used for monitoring and evaluating CBR programs. These tools and methods were reported in varying levels of detail and showed an absence of internal consistency between the stages of the monitoring and evaluation, and of external consistency across the studies reported. The lack of detail and consistency would make systematic measurement of CBR program outcomes difficult and suggested the need for more rigorous and compatible monitoring and evaluation practices to be developed, trialled and evaluated (Lukersmith et al 2013). Further, a consistent approach adopted by CBR programs in monitoring activities would better inform CBR program managers and stakeholders. It would also enable external personnel and agencies to collect data within one or more programs over time and across programs and thereby facilitate the development of a stronger evidence base on the efficacy and effectiveness of CBR.
- A second analysis of the same literature also commenced in 2011, seeking to explore the potential of the ICF to support CBR and its monitoring. From each study ‘information items’ were extracted; consistency among authors in identifying these items was established. The resulting information items were coded to ICF domains and categories, with consensus on coding being achieved (Madden et al 2013a). Approximately one third of the information items identified (788 or 32% of 2,495) in these articles related to concepts of functioning, disability and environment, and could be coded to the ICF. These information items were spread across the entire ICF classification with a concentration on Activities and Participation (49% of the 788

information items) and Environmental Factors (42%). The conclusion was that the ICF is a relevant and potentially useful framework and classification, providing building blocks for the systematic recording of information pertaining to functioning and disability, for CBR monitoring and evaluation. During the same analysis, 1,707 'non ICF' items were also extracted, and were preserved, so that the two sets of 'information items' from the literature would inform the construction of the monitoring toolkit, most especially the Menu which by then had been decided on.

In late 2011 the first of two workshops was held at the University of Sydney, involving 9 people from 3 countries in Asia (Vietnam, Lao PDR and the Philippines) who were experienced in the management of CBR and similar programs. The workshop was held as part of the (then) AusAID leadership development program. Focussed on information, it involved training on the ICF and CBR. The workshops proved to be the template for of the information design methods outlined in the Manual (see also Madden et al 2013b).

Participants described their information needs and worked though the types of questions and exercises now set out in the Manual, in Section 4 (Step 2). One of the outcomes of the workshop was an organised list of information items of importance to these CBR managers. The workshop also provided the opportunity to understand the similarities and differences of information needs, and the importance of CBR stakeholders being able to identify their own information priorities. The idea of a Menu of items was confirmed (emerging from the previous idea of a data dictionary). The first framework for the Menu was one of the major outputs of the workshop, along with the information items generated by workshop participants.

The other major outcome of this first workshop was the crystallisation of the most useful and feasible elements of a monitoring toolkit:

- a Menu of information items from which CBR managers and stakeholders could select for monitoring purposes; and
- an accompanying Manual to provide guidance on the use of the Menu, including the important process of deciding information needs and use.

The Menu would provide common building blocks for monitoring while the Manual would provide advice on how to use the Menu to create a monitoring system to suit the information needs and circumstances of different programs and communities.

Over subsequent months the Menu framework and items from this first workshop were brought together with the items from the analysis of literature (both the ICF and non-ICF items). A process of thematic analysis, consensus seeking and review enabled the items in the Menu to be 'winnowed down' and the framework to take shape, with items and examples from the literature and the workshop being organised into lists of similar groups – and items mentioned only seldom in the literature being discarded.

A second workshop took place in early 2013, this time with Pacific region partners – DPO and CBR stakeholders from PNG, Fiji, Solomon Islands and Timor Leste. Among a number of activities during the workshop, information needs were again discussed, starting from a 'blank sheet' with no reference to the previous work and existing draft menu. These ideas, information items and lists were documented, and the University of Sydney team then

combined the new ideas with the previous framework of the Menu. The resulting blended framework was then presented to and discussed with the course participants, with some further revision resulting. New items for the Menu were added to the Menu, and methods and principles developed for and during the workshop were recorded for use in the Manual.

The draft Manual and Menu were reviewed by the project advisory group, which had been formed during 2103, and revision took place. Final drafts were reviewed in early 2014, again by the advisory group and also by a wider group of reviewers, from academic, NGO, DPO and CBR practitioner backgrounds.

The first version of the Manual and Menu were finalised with the benefit of these reviews. They are ready and freely available for testing or use, and can be downloaded from: sydney.edu.au/health-sciences/cdrp/cbr-monitoring/.

Appendix 3: Example of template for planning monitoring activities

Actions and resources	Person taking lead	Partners and stakeholders	Goal	Benefits and outcomes	Dates and timetable
Conduct and document information design workshops and discussions (Steps 1 & 2)					
Plan to fit monitoring in day-to-day processes (Exercises 3 & 4)					
Plan details of how monitoring information will be recorded – Plan resources for designing forms and computer records; obtain equipment Decide information sharing arrangements e.g. for checking records					
Test and implement your plan – including considering 'staging'					
Train all the people who will be involved					
Other steps developed locally (from Steps 1-3)					
Start monitoring (see Step 4)					
Analyse and disseminate information – via reports, media (radio, newspaper etc), stakeholder seminars (see Step 5)					
Schedule a review of monitoring activities					

(see Step 6)					
Ongoing matters to consider					
Involvement of PWD and DPOs in monitoring					
MM&M understanding: • The Menu • The Manual					
Resources and sustainability					
Networking, communication and knowledge translation, ongoing dissemination of information					
Other matters of local importance					

Appendix 4: MM&M examples using the CBR Matrix

The table below provides some examples of monitoring questions and information items from the Menu related to the CBR Matrix components (WHO 2010) and other cross-cutting themes. Refer to the recording guide in the Menu for suggestions for gathering information on the items.

CBR Matrix component	Cross cutting theme		
	Empowerment	**Participation, inclusion & mainstreaming**	**Community**
Health	General: Participants are empowered to manage their health and choose healthy behaviours Example question: *Do participants feel they can maintain their own health?*	General: Participants can and do access health services; health workers understand disability Example question: *In our region, do people with disabilities attend their local health clinic and find staff supportive?*	General: Is the program achieving our goal to link with more mainstream health services? Example question: *What is our environment like, in terms of numbers of health clinics? Are our staff talking regularly with health workers? Do we consider there are sustainable services for the health of our participants?*
	Example items: **P2.2 Activities and participation** 5. Self care – satisfaction with **P4 Person – Outcomes** Empowerment (e.g. feelings of independence)	*Example items:* **P3 Person – Environment** 3. Health professionals are supportive 5. Health services are a facilitator for the person **P4 Person – Outcomes** Health (e.g. any unmet need for services) **03 Organisation – environment** Government support and structures Accessible mainstream services (e.g. villages which have a health clinic; services with information on clients with disabilities so that access can be monitored)	*Example items:* **03 Organisation – Environment** Government and community commitment, support and structures (e.g. number of health centres) **W4 Workforce – Responsibilities and tasks of staff/volunteers** How often our staff/volunteers talked to the health worker **04 Organisation – outcomes** Sustainability Networks and community linkages Referral arrangements Links with mainstream services

Education	General: People with disabilities aspire to formal education and can access it. Example question: *Is education important to our participants, and are they satisfied with their participation?*	General: In what ways can we say mainstreaming of education is happening? Example question: *Are more children with disabilities attending mainstream primary schools? Are schools accessible?*	General: Are we linking effectively with the community to promote mainstream education opportunities for our participants? Example question: *Are our program activities for promoting and supporting inclusive education helping mainstream schools to include children with disabilities? Does our teacher support and awareness program help to change their attitude towards disability?*
	Example items: **P2.2 Activities and participation** 1. Learning and applying knowledge – satisfaction with (includes choice, importance, opportunity) 8. Education – satisfaction with (includes choice, importance, opportunity)	*Example items:* **P2.2 Person – Activities & Participation** 8. Education – extent of participation **03 Organisation - Environment** Government support and structures Accessible mainstream services (education)	*Example items:* **A1.3 Activities targeting the community** Improving access to mainstream services e.g. • Promoting inclusion in mainstream schools • Teaching school staff basic rehabilitation needs and techniques • Remove/reduce environmental barriers to mainstream services • Providing or lending special resources to mainstream services e.g. schools **A2 Activity – Outcomes** Are services effective (e.g. influence on school staff; accessibility to services improved) **P3 Person – Environmental Factors** 3. Attitudes Of person in authority (e.g. teachers)

Livelihood	General: Are people with disability empowered to participate in economic life and are their incomes improving? Example question: *Has household income increased for persons with disabilities involved in our vocational program?*	General: Is our program contributing to improving livelihood for our participants? Example question: *Which of our two vocational training and employment support projects have better results with people gaining a job?*	General: Are our organizational strategy, resources and activities consistent? Example question: *What are our community links with employers and what are community attitudes about people with disability participating in work?*
	Example items **A1.2 Activities targeting people & families** Education and skills development Vocational training Self help groups Financial aid Provide microcredit or loan **A2 Activity–Outcomes** **What did the activities accomplish?** Examples: Economic benefits for participants (e.g. improved income after training) **P1.15 Living arrangements & conditions** Income/economic status – overall summary Living conditions – household summary **P4 Outcomes (summary)** Livelihood Examples: Household income; Financially self-supporting	*Example items* **P2.2 Activities and Participation** 8. Major Life areas Vocational training Work and employment **P1.11 Employment status** **A1.2 Activities targeting people and families** Education and skills development *The organisation is likely to record a description of the two separate programs and who participated in each program.*	*Example items* **O1.3 Organisation–Strategy** Key relations, community linkages and stakeholders Employers **O2 Organisation–Resources** Stakeholders and community links Employers **A1.3 Activities targeting the community** Education and empowerment Link with and educate community (e.g. how many local employers has our organization communicated with over the past year?) **P3 Person – Environment** 3. Attitudes

Social	General: Do people with disability expect to participate in social life and do they have support to do so? Example question: *What factors in the environment are supporting social participation and which are barriers? Are there differences for people with different health conditions and disabilities?*	General: Are people with disability participating in community and social areas of life without discrimination? Example question: *Are people with disability able to participate in religious practices in their local community?*	General: Are community attitudes about the participation of people with disabilities changing? Example question: *Has our disability awareness workshop changed some people's attitude in the village?*
	Example items **P3 Person – Environmental factors** 1. Products and technology (including built environment) 3. Support and relationships 4. Attitudes 5. Services system and policies (e.g. DPO) **03 Organisation – Environment** Community supports (e.g. DPO membership) **P1.8 Health condition/diagnosis** **P2 Functioning and disability** Body functions Activities and participation	*Example items* **P2.2 Activities and Participation** 9. Community, social and civic life Religion and spirituality – Extent of participation; satisfaction with participation **P3 Person – Environmental factors** 3. Support and relationships People in positions of authority (e.g. religious leader) Family Neighbours and community members 4. Attitudes People in positions of authority Family Individual attitudes in community Social norms and practices	*Example items* **P3 Person – Environmental factors** 4. Attitudes People in positions of authority Individual attitudes in community Social norms and practices **A1.3 Activities targeting the community** Link with and educate community and groups Awareness raising (among community, media, opinion leaders etc.) **A2 Activities – Outcomes** Improved community attitudes

Notes:

1. See Menu for further details of information items and suggested recording guides.
2. For any items where you want to monitor change over time, decide how often you will record information e.g. every month, twice per year, once per year.
3. In this table, the CBR matrix component, Empowerment, is treated as a cross-cutting theme.