

Monitoring Manual & Menu (MM&M)

for CBR and other community-based disability inclusive development programs

Menu

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Centre for Disability Research and Policy University of Sydney

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

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INTRODUCTION

The Monitoring Manual and Menu (MM&M) provide 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.

This document contains a 'Menu' of information and data items which can be used for monitoring CBR and other disability-inclusive community development programs with similar broad aims. The accompanying Manual explains the purpose and development of the Menu, and its links to the CBR Guidelines and the UN Convention on the Rights of Persons with Disabilities (CRDP); it provides guidance on how to plan and design monitoring activities, and how to use this Menu, in collaboration with program stakeholders.

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*—personal profile of staff, knowledge and skills, responsibilities and tasks, training undertaken, 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.

In this 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.
 [As a general rule (for many items), it is useful to allow for recording a 'do not know' option,
 to indicate information you want is missing.]

Person **Program** P1 Person—Personal profile and O1 Organisation – Purpose, structure & strategy history O1.1 Purpose statement (e.g., Goals; Geographic scope; Principles) P1.1 Name O1.2 Structure P1.2 Address (e.g., Sector; Structures and roles) P1.3 Geographic location O1.3 Strategy P1.4 Age – Date of birth (e.g., Priorities; Service plans; Key relations, P1.5 Gender community linkages and stakeholders; Information, P1.6 Cultural or other group reporting, communication) P1.7 Language P1.8 Health condition/diagnosis O2 Organisation - Resources P1.9 Health-related history, factors and (e.g., Funding/income: Expenditure: Stakeholders and community links; Knowledge resources) P1.10 Date(s) of onset of health condition. disability O3 Organisation – Environment P1.11 Education (e.g., Government and community commitment: P1.12 Employment status Community knowledge of disability and support of CBR; P1.13 Occupation Socio-economic and cultural profile of community) P1.14 Marital status P1.15 Living arrangements and conditions O4 Organisation - Outcomes (e.g., Sustainability; Environmental strengths) P2 Person—Functioning and disability P2.1 Body functions (Mental functions; Sensory functions A1 Activities – What is done and pain; Voice and speech functions; A1.1 Planning and managing the activities Functions of the heart and blood, (e.g., Planning and preparing services) resistance to infections, and respiratory Activities targeting people and families systems; Functions of processing food (e.g., Counselling; Therapy; Financial aid; and drink in the mouth, and of the body Equipment, assistive devices; Education and skills processing and using the food and development; Support in participation) drink; Urinary, genital, and reproductive A1.3 Activities targeting the community functions; Functions of the nerves, (e.g., Education—community and groups; joints, muscles and movement: Improving access to mainstream services) Functions of the skin and related structures) **A2 Activities – Outcomes** P2.2 Activities and Participation (e.g., How are services regarded? Do services adhere to (Learning, applying knowledge; General tasks and demands; Communication; CBR principles? Are services effective?) Mobility; Self care; Domestic life; Interpersonal interactions and relationships; Major life areas; W1 Workforce - Personal profile of staff Community, social and civic life) (e.g., Volunteer or paid staff; Gender (sex); Payment to staff; Qualifications; Date of entry and exit) P3 Person - Environmental factors W2 Workforce - Knowledge and skills (ICF) (e.g., Goal writing & plan development; Client training; (Products and technology; Natural environment Book keeping; Mobilising the community) and human-made changes to environment; Support and relationships; Attitudes; Services, W3 Workforce - Responsibilities and tasks systems and policies) (e.g., Getting the community involved; Training and education of Staff; Referral) P4 Person - Outcomes (e.g., Health; Education; Livelihood; Social; W4 Workforce – Training undertaken Empowerment) (e.g., Disability and the needs of people with disabilities; Community development; Assessments) W5 Workforce - Quality of performance

(e.g., Meets targets and demands; Trustworthy; Interest in

working in low resource or rural settings)

In the Monitoring Menu, there are four **groups** (Person, Organisation, Activities, Workforce), each with 1-4 **sub-groups**, many of which are further divided into **topics** (see Table 1 above). On the following pages of the Menu, you will see that each topic represents or contains **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.
 [Sometimes in the Menu international standards are suggested, making comparisons
 across services and even countries possible. Sometimes such standards do not exist
 or need to be adapted to suit local needs.]

The Menu is structured around some key people or parties (entities) involved with Community-based Rehabilitation (CBR) and other community-based disability inclusive development programs: a **participant**, **usually a person** with disability whose day-to-day participation and rights are of central concern; an **organisation** responsible for implementing the program and aiming to change the situation for the participant and support development in the community; the organisation and its '**workforce**' (both paid and unpaid), undertake **activities** designed to reach the goals of the participant, families and the community, the organisation and their stakeholders. The cross cutting themes of family, community, participation and empowerment are included in each of the groups.

Information items are the building blocks for statistics, indicators and reporting generally.

The Menu **does not** provide advice on how to design an information system; it is about the items that go into such a system, whether they are recorded as words, numbers or codes, or whether they are part of a large computerised system or a small paper-based record system.

Please remember when you read this document:

- 1. No program is likely to collect all the information and data items listed in the Menu
- 2. The Menu offers possible **information and data items useful for locally controlled monitoring**. These are items which, based on collaboration, consultation and literature review, appear to have significance in the field.
- 3. The process of selection of items from the Menu relies on collaboration and consultation among stakeholders interested in the information that can be produced.
- 4. The items do not represent all of the information that an organisation might collect for administrative purposes. There may be other information that needs to be collected but it is not discussed here, e.g. sources of referral to and from the CBR service; person's prior service use.

PERSON

This group of items relate to a person ('the **participant'**) – a particular person whose improved personal outcomes are of key interest in the program – usually a person with disability.

Other stakeholders – the person's family, members of the community in which the person and the program are situated, and others – are also of key importance and are recognised in various places in the Menu.

P1 Person - Personal profile and history

P.1.1 Name

Definition: Word(s) by which a person is known, spoken to, or referred to.

Significance and use: A person's name (or names) is generally recorded for administrative reasons.

Recording guide: The name is usually recorded in words, in enough detail to ensure the person is not confused with someone else; this is important if one of the names is commonly used in the region. The name used in the birth certificate should be included; this has been found helpful in avoiding duplicate records and double counting. If the information is recorded on a computer, consistent spelling is needed, or records can be hard to locate.

Records with names are confidential. When collecting and recording information about people, programs must do so respectfully and according to ethical principles e.g. that people can access and check their records and that information is not shared without the person's permission (See Principle 7 in the Manual for more information).

P 1.2 Address

Definition: The particulars of the place where someone lives.

Significance and use:

Statistics about the 'permanent' addresses, of where all the participants usually live, can indicate: areas where the organisation has many participants, areas where participants are particularly disadvantaged, etc.

A person may have more than one address: where they live: where they can be contacted; where they are staying temporarily while seeking support or treatment. All of these addresses may be relevant for the administration of the organisation, and the organisation may choose to record more than one address.

Recording guide: The address(es) of a person must be recorded in adequate detail and updated regularly so that the person can be located by the program. If the area where the participant lives can be recorded numerically (e.g. postcode or district number) then it is easier to compile statistics.

P 1.3 Geographic location

Definition: A locality, district, place, situation, locale, province.

Significance and use: A brief description of the geography of the person's usual home is useful for understanding their situation, for instance in terms of access and available community resources.

Recording guide: Factors which might be useful to describe include:

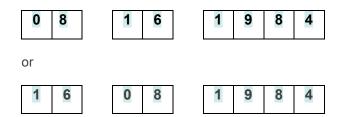
- Location rural, urban and other categories.
 Note: Because of national differences in the characteristics that distinguish urban from rural areas, there is no single definition of urban and rural location or population that would be applicable to all countries. National definitions are commonly based on size of locality. Population which is not urban is considered rural (from OECD quoting UN standards. (See OECD glossary of statistical terms: http://stats.oecd.org/glossary/download.asp).
- **General accessibility:** Accessibility might be recorded as a general description (in words), e.g. roads not accessible to vehicles; seasonal or other effects on road and route access, e.g. monsoon rains, border controls; lack of internet or mobile phone access
- **Distance from services**: A summary of the distance of the person's home from relevant services, such as schools or health clinics, is useful to track over time in a monitoring system, as this information may change and affect the participant's access. 'Distance' may be described in terms of e.g. kilometres or time or transport difficulties, and may recognise variation through the year e.g. during the monsoon.

P 1.4 Age - Date of birth

Definition: The day, month and year when the person was born.

Significance and use: 'Age' is needed as part of a profile of service users e.g. the ages of people in school or in paid work. Knowing the age of people using services also enables comparison with population data – e.g. it might be that younger children with disabilities are less likely to go to school than older children or other children their age. The age of participants is usually also important in designing and providing appropriate services. **Recording guide:** Age in years is usually published in statistics, rather than dates of birth (for privacy and other reasons). However collecting date of birth enables age at any time to be easily calculated.

For a person born on 16 August 1984, date of birth could be recorded according to local practice, e.g.



If the actual date of birth is unknown, estimate and record the year of birth.

If a person's age (rather than date of birth) is recorded, it is important to record when, e.g. that the person was 30 years old on 2 February 2013. Otherwise it is not possible to know the age at a later time without asking again.

P 1.5 Gender

Definition: Whether the person is male or female.

Significance and use: This information is needed if data need to be categorised by gender/sex. Generally this information is coded using a code list.

Recording guide: A possible code list is: 1. Male; 2 Female; 3. Unspecified or other.

P 1.6 Cultural or other group

Definition: A socially defined and recognised group of people who identify with each other based on shared history, beliefs, or experience.

Significance and use: Terms such as cultural group, religion, race, tribe or ethnic background are often not defined. The terms do not mean the same as each other, and each one may have different significance in different settings. Users of this menu may wish to define or separate these ideas in the records, depending on what is locally relevant. It may be important to know this type of information when designing services or in monitoring access by different groups of people.

Recording guide: It is suggested that the organisation, together with program stakeholders, discuss, decide and define whether this item is needed i.e. whether any such characteristics of participants are relevant to:

- · the services provided
- · the way the service is provided
- · the preferences of participants
- the way in which the service may be monitored or evaluated (e.g. in terms of equity).

The most relevant term(s) can then be selected for recording.

A list of possible options relevant to the area could be created which would enable statistics to be prepared at times, e.g. if the religion of participants affects the service, a list of common local religions with tick boxes could be created.

P 1.7 Language

Definition: A shared and agreed system of symbols to help communication between humans. Language can be spoken, written or signed. Ways of communicating may include gestures, facial expressions, actions etc.

Significance and use: The organisation may need to know a person's preferred language for communication (including sign language and other non-verbal communication). [This may differ from the language spoken at home and it may be important to record more than one language.] This information may also be needed for planning and monitoring the services (e.g. in terms of equity of access or improving staff language skills).

Recording guide: Using a (numbered) list of common languages used by stakeholders would allow statistics to be prepared at times.

P 1.8 Health condition/diagnosis

Definition: Diseases, disorders and injuries.

Significance and use: Functioning and disability arise from interactions between health conditions and environmental factors (according to the ICF), so that an understanding of health condition(s) may assist with understanding a person's needs and some of the difficulties they experience. Knowing the main health conditions of all participants may help with planning services and monitoring trends in the needs of participants. It is important that the diagnosis is accurate, especially if it affects treatment; diagnosis by a medical practitioner is considered the most reliable source of this information.

Recording guide: If it is important to know about stakeholders' health conditions, please refer to the International Classification of Diseases (ICD) for an international standard list: http://apps.who.int/classifications/icd10/browse/2010/en. Locally relevant short lists of conditions from ICD can be compiled to suit stakeholders' interests.

P 1.9 Health-related history, factors and behaviours

Definition: A cluster of health-related factors and behaviours relating to the person. **Significance and use:** It may be important to know and to record habits, factors or behaviours that affect the person's health (e.g. physical activity, alcohol and drug use, violence or abuse, nutrition, weight) and also major events and troubles or upheavals in the person's past life (such as loss of family, injuries). This information may help in understanding their situation and difficulties, and may also indicate actions to be taken by the person, the service providers or other stakeholders. As part of ongoing data about the program, it might also show patterns of change in the behaviours of participants.

Recording guide: This information would generally be found in discussion with the person and possibly their family, and would be recorded as text (in words).

P 1.10 Date(s) of onset of health condition, disability

Definition: The date(s) or year(s) when the person first experienced the health condition (injury or illness), and first experienced disability (e.g. difficulty with activities). These may be two different dates.

Significance and use: Such information may be used to understand the person's experience over the years. This experience may vary according to whether they have had the condition since birth, had an injury, or whether their disability is related to a disease. It may sometimes be valuable in planning or monitoring services to know whether people have had disability most of their lives (early onset) or whether they and their families are in the early stages of coming to terms with new difficulties in their lives, but have had previous opportunities (e.g. education). Statistics on dates of onset can be useful; for instance a natural disaster (such as floods) or industrial accident might give rise to disabilities.

Recording guide: It would be best to record the dates as for date of birth; this allows age at onset and the duration of the condition or disability to be calculated from the difference between dates.

P 1.11 Education

Definition: The knowledge or skill obtained or developed by a learning process, often via systematic instruction, especially at a school, college or university.

Significance and use: In many countries 'education level' has been found to be a useful socio-economic indicator which is used in statistical analysis, for instance to investigate services as well as many health and other personal outcomes.

Knowing if, what and where a person is currently studying is important information, and may help in planning services. It is useful to record this information using local terms, to show a student's experience and progress over time, e.g. better access to school.

Monitoring an increase in the number of participants accessing education, for instance, would be an interesting outcome indicator for the service and organisation overall, and may help form a general view of access to education by participants of the program.

Recording guide: Two main pieces of information are likely to be of interest:

- **Education level:** The highest level of an educational program the person has successfully completed. See UN data glossary: http://data.un.org/Glossary.aspx. Refer also to ISCED for education levels: www.uis.unesco.org/Education/Documents/isced-2011-en.pdf
- Current educational participation: As well as recording if someone is participating in
 education it may be useful to record what kind of place they are attending e.g. school,
 college, technical or vocational school, work skill training program. In many countries a

distinction is made between 'mainstream schools'; 'special schools'; and special programs and support within 'mainstream schools'.

P 1.12 Employment status

Definition: Engagement in paid work activities, whether as an employee or self-employed. **Significance and use:** Whether or not a person is employed and being paid for work is important information about the person's participation and their economic status. It is important to monitor changes over time – for the person and as a summary of the program's outcomes. It may be of interest to compare employment rates among participants with those of the broader community.

Recording guide: Employment status is often recorded as:

- 1. Employed
- a) Person is paid a wage.
- b) Person is 'employed', with agreed responsibilities, and receives some payment, e.g. for expenses, but not a full wage
- 2. Unemployed
- a) Person has no employment, and
- b) Person is available to start work, and
- c) Person actively seeks employment.
- 3. Not in the labour force these are people who are not looking for work and not therefore unemployed

[In official statistics each of these options usually relates to a particular time period e.g. one week.] Additional information on hours worked, duration of employment contract etc. will give an even better indication of the person's situation.]

P 1.13 Occupation

Definition: Type of work being done by an employed person (or the type of work done previously, if the person is unemployed).

Significance and use: Information on a person's occupation can reveal any mismatch between a person's skills and occupation, and can assist in working out the person's needs e.g. for training. This item can also be an important component of understanding environmental barriers at work, or for identifying opportunities for linking with employers or other organisations in the community.

Trends over time may be of interest, in monitoring change in the participant profile of the organisation.

Recording guide

It is suggested that relevant lists of common local occupations are created and used. See the International Standard Classification of Occupations (ISCO-88) International Labour Office, Geneva, 1990: http://www.ilo.org/public/english/bureau/stat/isco/.

It may also be of interest to record, in addition, the type of business or industry the person is working in (e.g. small business, weaving, farming).

See the International Standard Industrial Classification of All Economic Activities, Rev.4 [http://unstats.un.org/unsd/cr/registry/regcst.asp?Cl=27]

P 1.14 Marital status

Definition: Civil status: Legal, conjugal status of the individual in relation to the marriage laws or customs of the country. See UN data glossary: http://data.un.org/Glossary.aspx. **Significance and use:** Marital status is often useful in administration (e.g. with details, it can be needed to ask for treatment for emergency or acute conditions; similar information on 'next of kin' is also used for this purpose). It is an important part of understanding the person's family situation and responsibilities. It might also be useful for statistics on groups of participants e.g.; for instance, better health for men is often linked to being married. **Recording guide:** As an example, categories used in the Australian census are:

- Never married
- 2. Widowed
- 3. Divorced
- 4. Separated
- 5. Married (note that this category includes 'de facto' marriages of people who have been partners for a long time)
- 6. Not applicable

See: http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2901.0Chapter6902011

P 1.15 Living arrangements and conditions

Definition: A set of related information designed to summarise features of the person's socio-economic situation that are not captured in other items.

Significance and use: Other items in the Menu record a person's employment, family situation and environmental facilitators and barriers. The items suggested here relate to other features e.g. a description of housing, the household structure (which may be different from 'family') and socio-economic indicators such as income and overall living conditions. This information is useful for understanding the person's situation, and being better able to assist them.

An accurate description can help track progress over time.

Statistics compiled from this information could help highlight possible disadvantages of groups of service users and needs for further support.

Recording guide: This information item may cover:

- What kind of housing the person lives in, e.g. grass or wooden house, apartment
- Who they live with household and family members (and relationships), their strengths and needs
- Income/economic status, family assets. (This might contain financial detail if relevant or might be just a statement of income compared to the general population e.g. 'low', 'average' or 'high' income.)
- Living conditions a summary of the overall socio-economic situation of the household; household strengths and needs.

Note: Other relevant information is in other items and should not be included here; for example, if the quality of local services such as water supply and sanitation need to be recorded, use item P3 (the person's environmental factors – domain 5).

P2 Person - Functioning and disability

A person's functioning and disability, and related environmental factors, can be recorded using the International Classification of Functioning, Disability and Health (ICF) as the framework and classification. According to the ICF, functioning and disability relate to body functions and structures, activities and participation, and arise from the interaction of health conditions and all physical, social and attitudinal factors in the person's environment (WHO 2001). This world standard framework is relevant to CBR (see Madden et al 2013), to UNCRPD (see Madden et al 2012) as well as disability policy more generally (see WHO & World Bank 2011; WHO 2014). The ICF is the basis for the Menu items on functioning and disability (P2) and environmental factors (P3).

P2.1 Body functions

Definition: Body functions are the physiological functions of body systems (including psychological functions) (*WHO 2001*).

Significance and possible use: Knowing the common body functions affected in a group of program participants enables organisations and stakeholders to decide what services, particularly health services may be important. In addition, knowing about body functions of participants helps build up a complete picture of disability in the community.

Recording guide: Two aspects of body functions are recorded: 1) whether the person experiences problems with any of the following body functions (see domains in following table); and 2) if so, how great is the problem. Two scales for this are suggested from which the user may choose. The first, simpler scale may suit organisations where severity can be rated by those working with the participant. The second, more detailed scale may suit some organisations where professional assessment is a key feature. Testing any scales to be used, and then training staff in their use will be an important step in being ready for monitoring (see steps in Manual).

Body functions—extent of impairment

Domain of body function	 0 - No impairment 1 - Some impairment (mild to moderate) 2 - Severe impairment (including 'complete' specified) 9 - Not applicable 	 0 - No impairment 1 - Mild impairment 2 - Moderate impairment 3 - Severe impairment 4 - Complete impairment 8 - Not specified 9 - Not applicable
1. Mental functions Examples: Confidence; Problem-solving; Attention; Memory; Consciousness; Regulation of emotion; Energy and drive (e.g. impulse control); Psychomotor control (e.g. restlessness)		
2. Sensory functions and pain Examples: Seeing and related functions; Hearing and vestibular functions; Pain; Other sensory functions (e.g. touch, proprioceptive)		
3. Voice and speech functions4. Functions of the heart and blood		

Domain of body function	 0 – No impairment 1 – Some impairment (mild to moderate) 2 – Severe impairment (including 'complete' specified) 9 – Not applicable 	 0 – No impairment 1 – Mild impairment 2 – Moderate impairment 3 – Severe impairment 4 – Complete impairment 8 – Not specified 9 – Not applicable
resistance to infections, and respiratory systems		
5. Functions of processing food and drink in the mouth, and of the body processing and using the food and drink		
6. Urinary, genital, and reproductive functions		
7. Functions of the nerves, joints, muscles and movement		
8. Functions of the skin and related structures		

Users can

- Use this list of body functions as it is
- Split out the examples for separate collection (for instance CBR stakeholders may wish to differentiate between people with seeing and hearing difficulties)
- Refer to the ICF to get more detailed examples of body functions (WHO 2001 and http://apps.who.int/classifications/icfbrowser/).

Even with a standard list, you may wish to keep an 'other' category to record a body function not included in your standard list.

Body structures

Definition: Body structures are the anatomical parts of the body, such as organs, limbs and their components (*WHO 2001*).

Some programs may not wish to collect this information. Some CBR programs have included: Structures related to genitourinary and reproductive systems; Structures related to movement (e.g. loss of limb). For CBR programs interested in using this concept, please refer to the ICF (WHO 2001 and http://apps.who.int/classifications/icfbrowser/).

P2.2 Activities and Participation

Definition: Activity is the execution of a task or action by an individual. Activity limitations are difficulties a person may have in executing activities. Participation is involvement in a life situation. Participation restrictions are problems a person may experience in involvement in life situations (WHO 2001 and http://apps.who.int/classifications/icfbrowser/).

Significance and possible use: Knowing a person's participation and activities in all domains of life is important in understanding their situation, their difficulties and the areas on which they wish to focus and bring about change. 'Participation' provides a positive framework in which to report on outcomes in relation to human rights, and needs and unmet needs generally. Numerical (quantitative) data on participation and activities can be

summarised across the organisation or across groups of people, to produce statistics. These data can be supplemented by comments and other forms of descriptive information (qualitative data). Reporting outcomes is easier if people's goals are recorded using the same framework.

Recording guide: All of the nine chapters (life areas) of ICF Activities and Participation are likely to be relevant to all people. Goals, current status, or problems can be recorded at any level – chapter level (see nine headings in the table below) or using items within chapters as illustrated (see more options within the ICF – WHO 2001).

The following table offers four types of response (Difficulty with activity; Need for assistance with activity; Participation restriction; and Satisfaction with participation), which can be used in any life area (WHO 2013:24 citing Australian national data standards). Satisfaction is the person's rating of their satisfaction with participation in a domain of life, in relation to their current goals; it summarises the concepts of choice, opportunity and importance.

These four options can be useful for recording problems or discussing goals and deciding what to work towards, as well as for monitoring progress, in any life area. What is recorded is what is important to stakeholders. Recording scales are suggested below. Users may decide to simplify the scales for local use, e.g. Participation restriction could be recorded as: 0 – Full participation; 1 – some restriction; 2 – Severe or complete restriction. Testing any scales to be used, and then training staff in their use will be an important step in being ready for monitoring (see steps in Manual).

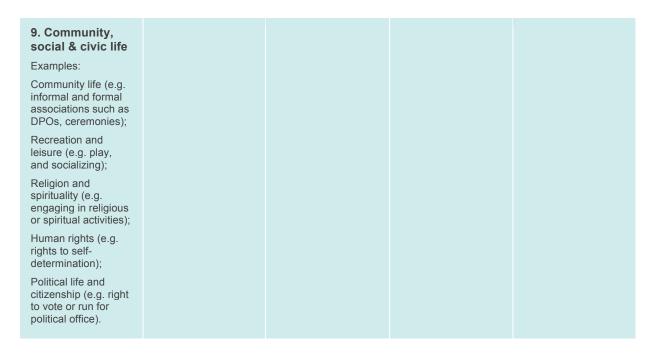
You may decide to use another measure of activity or participation, e.g. the number of times someone does an activity such as helping in the home (domain 6 – domestic life), the number of years someone has attended school (domain 8 – major life areas – education).

Activities and Participation: domains and recording scales

Domain of life (Activity, Participation)	Options for recording			
	Difficulty with activity	Need for assistance with activity	Participation restriction	Satisfaction with participation
	 No difficulty in this life area Mild difficulty Moderate difficulty Severe difficulty Complete difficulty Not specified Not applicable 	 Does not need help/supervision Sometimes needs help/supervision Always needs help/supervision Unable to do this life area, even with assistance Not specified Not applicable 	 Full participation Mild participation restriction Moderate participation restriction Severe participation restriction Complete participation restriction Not specified Not applicable 	 High satisfaction with participation Moderate satisfaction Neither satisfied nor dissatisfied Moderate dissatisfaction Extreme dissatisfaction Complete restriction and dissatisfaction Not specified Not applicable

1. Learning, applying knowledge Examples: Reading; Writing; Calculating; Solving problems; Making decisions.		
2. General tasks and demands Examples: Carrying out daily routine.		
3. Communication Examples: Communication with spoken messages; Communicating with nonverbal messages including body language, signs and symbols, pictures; Communication with formal sign language messages.		
4. Mobility Examples: Changing and maintaining body position (e.g. sitting, standing); Carrying, moving and handling objects (e.g. reaching for objects; fine hand use); Walking and moving (e.g. moving around within the home, moving around outside the home and other buildings or using transportation).		
Examples: Washing oneself; Toileting including regulating urination, defecation and menstrual care; Dressing; Eating; Drinking; Looking after one's health including ensuring comfort, managing diet and fitness, maintaining one's health.		

6. Domestic life		
Examples:		
Acquisition of goods and services including shopping, acquiring a place to live, gathering daily necessities such as water;		
Household tasks including preparing meals, doing housework, washing clothes, caring for household objects such as furnishings, appliances, vehicles, devices.		
7. Interpersonal interactions and relationships		
Examples:		
Complex interpersonal interactions (e.g. forming, maintaining and managing interactions with other people);		
Regulating behaviours and interactions;		
Family relationships;		
Intimate relationships.		
8. Major Life areas		
Education		
Examples: School education including pre-school;		
Vocational training.		
Work and employment Examples: Acquiring, keeping and terminating a job; paid employment; apprenticeship.		
Economic life and self-sufficiency Examples: Engaging in economic transactions - simple (e.g. using money to buy food, barter, or save money); or		
complex (e.g. maintain a bank account); Having the resources to ensure economic security.		



<u>Note</u>: There are recommendations for national census questions on disability which relate to the ICF; there is value in having some program data which relate to the census data. The six questions seek information on difficulty with seeing; hearing; remembering or concentrating (in body function item P2.1 – domains 1 and 2), walking or climbing steps; self-care such as washing or dressing; communication (item P2.2 – domains 4, 5, 3 in table above). See http://www.cdc.gov/nchs/washington_group/wg_questions.htm).

P3 Person – Environmental factors (ICF)

Definition: The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning.

Significance and possible use: Environmental factors can impact a person's functioning and disability significantly. Frequently it is environmental factors which must be changed in order to improve a person's functioning e.g. improvements to physical environments; changes to school policies and practices; work with communities to help improve attitudes to disability; overcoming difficulties using a service (e.g. why a person is not attending).

Understanding relevant environmental factors is important in service provision. Environmental factors, as a component of the ICF, have been found highly relevant to CBR (Madden et al 2013). By combining the information across the organisation a picture can be obtained about which environmental factors are the biggest problems for participants.

Knowing this information empowers the organisation and its stakeholders to participate in policy debate and development, for example about improved inter-sectoral coordination. For example, this information might mean the organisation could advocate for improved health services, by knowing how many members of the community were disadvantaged by poor access to these services, and how this affected their activities and participation (item P2). Such information also can be relevant in national policy discussion.

Recording guide: There are five types of environmental factors listed in the ICF which are likely to be relevant to all people (five chapters of ICF Environmental Factors). Factors can be

recorded at any level – chapter level (the five chapters are headings in the table below) or using items within chapters as illustrated. The table below can be used to record the influence on the person's functioning, simply (e.g. using a tick) to indicate whether an environmental factor (at chapter or more detailed level) is a facilitator or barrier – or both. <u>Alternatively</u>, a number could be used to show to what extent any factor is a facilitator or barrier e.g. using a 'scale' of 0 or 1, or using simple tick box options).

You may wish to add detail in some categories e.g. if a 'person in authority' (domain 3) is a facilitator to a person's participation you may wish to record some detail e.g. whether it is a religious leader or village chief; or you may want to record details about specific products (domain 1) used in your community. These additional categories or examples are up to you. (Examples of items within chapters were developed with collaborators and from the literature. More options are available in the ICF (WHO 2001 and http://apps.who.int/classifications/icfbrowser/)).

Environmental factors: facilitators or barriers

The following environmental factors influence the person's functioning either: • as facilitators • as barriers	Facilitators	Barriers
	+0 – Not a facilitator +1 – Mild facilitator +2 – Moderate facilitator +3 – Substantial facilitator +4 – Complete facilitator +8 – Facilitator not specified 9 – Not applicable	 0 – Not a barrier 1 – Mild barrier 2 – Moderate barrier 3 – Severe barrier 4 – Complete barrier 8 – Barrier not specified 9 – Not applicable
1. Products and technology		
 Examples: Products for personal consumption including food and drugs/medicines Products and technology for personal use in daily living Products and technology for personal indoor and outdoor mobility and transportation Products and technology for communication Productions and technology for employment Assets (e.g. money, house, household goods, knowledge and skills) 		
2. Natural environment and human-made changes to environment		
Examples: Air or water quality, natural events (storms, earthquakes)		
 3. Support and relationships Examples: Family (immediate and extended) Cooperation, participation Acquaintances, peers, colleagues Neighbours and community members People in positions of authority Health and other professionals 		

4. Attitudes

This domain includes all types of attitudes and beliefs (including beliefs about health) that affect the environment of the person.

Examples:

- · Attitudes of family members
 - o Awareness, acceptance, confidence
- Individual attitudes of acquaintances, peers, colleagues, neighbours and community members
- Individual attitudes of people in positions of authority, personal care providers, teachers, other professionals
- · Societal attitudes
 - o Media messages
 - o Awareness, acceptance
- · Social norms, practices and ideologies

5. Services, systems and policies

Examples:

- · Housing services, systems and policies
- Utilities services, systems and policies e.g. water supply and sanitation services
- · Communications services e.g. Media
- · Transportation services, systems and policies
- Legal services, systems and policies e.g. relating to the UN Convention on the Rights of Persons with Disabilities
- Economic services, systems and policies
- Social security services, systems and policies e.g. benefit payments
- General social support e.g. DPOs, advocacy, support in daily living
- · Health services, systems and policies
- · Education and training services, systems and policies
 - o Participation of parent association
 - o School infrastructure
- Labour and employment services, systems and policies
- Services, systems and policies, other specified

P4 Person - Outcomes

Definition: The person's 'outcome' is defined here as being a summary of the person's overall well-being, participation and inclusion at the time of recording.

Note:

- Many other topics in the 'person' group can inform specific outcomes e.g. about people's
 activities and participation, employment and schooling. The purpose of the 'outcomes' subgroup is to summarise overall well-being, not to duplicate other 'Person' topics.
- Summarising people's overall outcomes can be done periodically, to review progress being made.
- Summaries of outcomes can be important and might be used in for evaluation, not only in monitoring.

Significance and possible use: This information can be used, with other information in the 'person' group of items (e.g. on functioning and disability, environmental factors, employment, education), to review progress with the person and to plan the future. While this information may contribute to an evaluation of the service and the organisation, there is no attempt here to identify cause and effect e.g. that the service 'caused' an improvement. For instance, any improvement in well-being may be partly due to the work of a service but may also be related to efforts of the person, support of the family and to community initiatives or environmental changes. The focus here is on the person and on knowing, overall: 'how is the person doing?'

Recording guide: A range of methods can be used to find and record this information. Discussions with the person and those close to the person are essential. It is likely that this information would be recorded infrequently, and might be discussed during regular progress reviews. There are five components of CBR which may be useful topics to be considered about the person's outcomes as defined here (see WHO et al 2010). Under each component heading, examples of information items are provided.

• Health e.g.

- Sustained general health; e.g. a standard question answered by the person (SF1) is "In general would you say your health is: Excellent, Very Good, Good, Fair or Poor?"; other suggestions include 'no time sick or in hospital'.
- Feelings of well-being
- o Participation in rehabilitation
- o Participation in community health programs
- $\circ\hspace{0.4cm}$ Unmet needs e.g. for equipment, or health or rehabilitation services

Note: not including 'health condition' – item P1.8, or 'body function – item P2.1.

• Education, e.g.

- o Engagement in school, e.g. days/terms/years attended
- Acquisition of new skills and capabilities
- o Successful transitions to different levels of schooling

Note: not including 'Education' details in item P1.13

Livelihood

- · Finances, e.g.
 - Household income, living conditions; finances as a way to achieve greater equality ('equal the playing field')
 - Financially self-supporting; ability to meet needs e.g. food, education, buying mobility aids, saving money, contributing economically, repayment of loan, having disposable income (e.g. buying jewellery, and gold as evidence that person is living well)
- Employment outcomes, e.g.
 - o Engagement and sustainability: job security; sustainability of person's business Note that this is a summary, possibly a commentary, and separate from the item on 'employment status' (item P1.11).

Note: not including 'Employment status' (item P1.11) or 'Living arrangements and conditions' (P1.15).

• Social, e.g.

- Active involvement in family and community activities, ease of integration into community, used to leaving the house; location of participant's house in the community
- Personal and family happiness and joy
- Unmet needs for support or environmental change

Note: not including 'Activities and Participation' information in item P2.2

Empowerment

- 'Agency', autonomy, choice and control, e.g.
 - Choice and control over care, living needs
 - Feelings of independence
 - Having a voice, 'sticking up' for oneself, agency and responsibility for oneself
 - o Family recognition and change in attitude about disability

- o Change in power, e.g. being the main breadwinner or equal contributor
- Change in opportunity
- · Community linkages: Connection to 'outside world', e.g.
 - Access to and use of local resources and services
 - Awareness of services and support
- Self-esteem, resilience, e.g.
 - o Dignity, increased self-concept, perception of self
 - Self-esteem, confidence facing the 'non-disabled world', positive body image, feeling capable/differently able not disabled, not feeling out of place, embarrassed or shy.

Note: not including information on 'Satisfaction with Activities and Participation in item P2.2 or the person's environmental factors (e.g., attitudes or systemic discrimination) in item P3.

ORGANISATION

This group of information items relates to the organisation (entity) which is responsible for and interested in the success of a community-based disability-inclusive program such as CBR. The organisation has relationships with people with disability (participants) (see P items) and other stakeholders. It seeks to advance the goals of the organisation and its participants, by undertaking activities (see A items) with its workforce, both paid and voluntary (see W items).

O1 Organisation - Purpose, structure and strategy

Users of the Menu are encouraged to create a record of these topics and information items, in words and other formats most useful to them, and to update them periodically. Stakeholders decide collaboratively what is to be monitored and what is most relevant in their community.

O 1.1 Purpose statement

Definition: What the organisation is trying to achieve; the reason the organisation was established. Sometimes this includes a 'vision' or a 'mission' statement'. Ideally the purpose provides a uniting reason for people working in and with the organisation.

Significance and possible use: A purpose statement is the most basic and important benchmark for determining success. The purpose of the organisation provides the criteria against which it can judge its progress and outcomes. Such information is often required by funders and external evaluators.

Recording guide: 'Purpose' may be described (usually in text/words) in terms of:

- **Goals:** What benefits are intended, what the organisation or program is trying to achieve (for people with disabilities, families, communities, the social environment)?
- *Target group*(s): Who are the intended recipients of the program who might benefit from it? e.g. family, community, environment and people (described in terms of e.g. age, disability, health condition).
- Geographic scope: e.g. district, village or region
- **Principles:** Values that guide choices about how the organisation works and the programs operate; includes ethical standards of the organisation, e.g.
 - Link to CBR principles (including UNCRPD principles)
 - o Participation (of all stakeholders) in planning and processes; inclusion
 - o Advocacy and self-advocacy; 'Nothing about us without us'
 - Accessibility of facilities and meeting places
 - Recognition of diversity and different needs
 - Equality: challenge stereotypes; gender equality; equality of opportunity; democratic processes;
 - o Self-reflection by organisation; commitment to monitoring and evaluation.

O 1.2 Structure

Definition: Framework of the organisation, outlining the legal and operational structure. **Significance and use:** The structure of an organisation is intended to provide order and predictability for planning and carrying out the organisation's work, as well as clarifying its legal responsibilities and formal links. Understanding and recording structure provides the context for monitoring the work and outcomes of the organisation.

Recording guide: Structure may be described in terms of:

- **Sector**: Government, Non-government organisation (NGO), Disabled People's Organisation (DPO); self-help group (SHG) etc.
- Structures and roles, e.g.
 - o Committees and membership,
 - Roles and responsibilities (e.g. of supervisors, staff, volunteers, persons with disabilities as staff; roles of SHGs and DPOs)
 - Team structures (if relevant)
 - Responsibilities of staff (e.g. prosthetics technician, medical staff, orthopaedics officer, physiotherapist, occupational therapist, speech pathologist, rehabilitation therapist, therapy assistant, audiologist, sign language trainer).

O 1.3 Strategy

Definition: How the organisation puts the 'Purpose' statement into practice.

Significance and use: Strategy keeps an organisation aligned with its purpose statement and seeks efficient and effective use of limited resources. Documenting the strategy enables this alignment to be monitored.

Recording guide: Each organisation will develop its own most suitable methods and strategies for achieving its goals. Strategy may be described in terms of:

- Priorities: A 'shortlist' of important objectives to achieve, which enable the organisation to connect broad goals to detailed plans; sometimes what the organisation decides to work on first, e.g.
 - the five CBR components (areas in which the organisation is working and seeking to have an effect): Health, Education, Livelihood, Social, and Empowerment
 - Improving people's functioning experience (including participation) and environmental factors (ICF)
 - Inclusion; 'Social integration'
 - o Communication with opinion leaders, with the community, with stakeholders.
- Service plans, e.g.:
 - Mainstreaming encouraging development and use of 'mainstream' services
 - Systemic advocacy (e.g. advocating change in schools policy)
 - Outreach
 - Information and advocacy
 - Special adaptations to local conditions
 - o Use of locally available material e.g. in making assistive devices
 - Use of local knowledge and experiences
 - Use of home-based programs.
- Key relations, community linkages and stakeholders: Relationships which the
 organisation has identified as particularly important to its success and the well-being of its
 participants and stakeholders. These are relationships to which the organisation decides,
 as part of its strategy, to devote effort to maintaining and enhancing, e.g.
 - Government (MPs, councillors, government departments)
 - Village chiefs and others
 - o DPOs
 - o NGOs
 - Faith based organisations

- o Mainstream services, e.g. education, health organisations
- Employers
- o Media.
- **Organisational processes:** Systems and methods to support and maintain the programs of the organisation (as documented and as done in practice), e.g.
 - o Intake and finalisation procedures
 - Staffing, selection and training processes
 - Staff code of conduct or ethics
 - Project administration: Manuals, guidelines, training, client selection (e.g. loan recipients); assessment methods (e.g. of child growth and development)
 - Contracts (with whom)
 - Loan applicant screening
 - Financial management
 - Communication and use of media
 - o Promotion, events, presentations.
- *Information, reporting, communication*: The systems for obtaining, storing, extracting, summarising and communicating information about the work of the organisation and the community; communication may be within the organisation or externally, e.g.
 - Reporting types and deadlines
 - Monitoring processes (relating to organisation's purpose and outcomes, service outcomes and person outcomes),
 - o Accounting, financial management
 - o Reporting; annual reports
 - o Information and communication system flows
 - o Information about the community, including unmet needs
 - Filing systems
 - Website

O2 Organisation - Resources

Definition: Resources are the assets of the organisation which allow it to function well and to achieve its goals; assets may include funds, materials, staff, relationships, networks and characteristics of the community and environment.

The items below suggest information that the organisation may need, but there may be different information required by stakeholders.

Significance and possible use: Having some understanding of the organisation's resources is important to planning and managing, and to understanding strengths and weaknesses. Areas where there may be opportunities to improve resources (e.g. without expenditure) may be identified, e.g. there may be community groups with similar goals, or mainstream services to whom participants can be referred. Accessing and using available resources is important for efficiency and effectiveness.

Recording guide: 'Resources' is a useful topic to include in planning workshops for the organisation (see Manual), perhaps especially information about 'Stakeholders and community links'; such discussion may give useful guidance about what to collect, and how. Funding, income and expenditure are likely to be recorded in the organisation's accounting system. Local standards and information required by funders are sometimes set out for the organisation. Resources may be described in terms of:

• Funding/Income, e.g.

- o Funding sources
- Client fees
- Client repayment of loans
- o Materials including donated goods
- Expenditure: Itemised according to local needs and standards. e.g.
 - Staff salaries, staff expenses (e.g. allowances, equipment, training, travel)
 - Client expenses (e.g. allowances, equipment, training, travel)
 - Office equipment
 - o Financial support for participants, equipment for participants
 - Information including monitoring and evaluation

Stakeholders and community links, e.g.

- o DPOs
- o NGOs
- Volunteers
- (Women and women's organisations)
- o Referral networks e.g. secondary and tertiary medical care
- Employers
- Community links and involvement

• Knowledge resources, e.g.

- o Practice guidelines and manuals
- o Internships, volunteers
- o Internet and written resources
- Knowledge about CBR.

O3 Organisation – Environment

Definition: All features of the organisation's environment, including its community, which may affect its work and its efforts to improve the well-being of its participants.

[Note that the contents here are described so as to avoid overlap with 'organisation resources' or 'person environment'.]

Significance and possible use: Understanding the broad environment of the organisation, including the community in which it operates, is important for CBR and disability inclusive programs or organisations, as they generally focus on changing aspects of the environment – e.g. services, or the physical or social environment. Identifying all factors in the environment which may impact (positively or negatively) on the organisation, its services and success, is the first step to knowing the key relationships that are important to focus on as part of its overall strategy (see 'organisational purpose' section).

Likewise, analysing information about the community and environment empowers the organisation and its stakeholders to participate in policy debate and development e.g. the types of information suggested here and in P3 (person's environment) could enable the organisation to advocate for improved health services, to know how many people are disadvantaged by poor access to these services, and to identify possible advocacy partners within the community (see also O2). This information can also be used in national policy discussions.

Recording guide: The items below suggest information that the organisation may need (others may also be recorded). The collection and periodic updating of this information would provide useful resources for: training new staff, reviewing change in relationships and environmental resources. Some examples of how information may be obtained are included in the lists of items below, in the 'Recording suggestions'.

Government and community commitment, support and structures, e.g.

- Accessible mainstream services (e.g. health, education, transport, banking)
- o Resourcing and support from health, education and transport systems
- Internet and mobile technology (e.g. internet cafes)
- Policies (e.g. accessibility, land use, support for CBR) <u>Recording suggestion</u> (previous 4 items): Some information may be available from annual reports of mainstream services (e.g. presence of health clinics in villages; what mainstream services do and spend; who their target groups are; their relationships with, and possible resources to, organisations such as CBR). Do they have information on clients with disabilities so that access can be monitored?
- Provision of 'back-up' and complementary services (e.g. training, referrals, sign language and interpreter training)
- Cross-sectoral coordination (e.g. relationship between local CBR supervisor and village administrator)
- DPO supports program participants
- Community based information systems (e.g. community centre, community meetings).
 <u>Recording suggestion</u> (previous 4 items): These items may be found through
 discussion in a stakeholder workshop.

• Community information, knowledge of disability and support of CBR, e.g.:

- Community leaders: positions and support for CBR organisation (e.g.: relationship with village administrators)
- o Community acceptance of CBR across religious and cultural boundaries
- Community acceptance of people with disability
- Community attitude to discrimination and abuse
 <u>Recording suggestion</u> (previous 4 items): These items may be found through discussion in a stakeholder workshop.
- Information about the community, population, community needs and unmet need for CBR.

• Socio-economic and cultural profile of community, e.g.

- Infrastructure of district in scope, including water, electricity, road quality, emergency preparedness
- Employment
- Industry
 - <u>Recording suggestion</u> (previous 3 items): Some information may be available from annual reports of mainstream services. Reports of national statistical organisations may provide statistics on employment and industry by region. Local knowledge can also be obtained from stakeholder workshops.
- o Community committees and groups e.g. women, youth
- Ideas and values of cultural groups
 <u>Recording suggestion</u> (previous 2 items): These items may be found in a stakeholder
 workshop.

O4 Organisation – Outcomes

Definition: The results the organisation is achieving, particularly in relation to its purpose and goals.

Significance and possible use: Summarising outcomes can be done by an organisation periodically, to review progress being made – what the organisation is achieving compared to its main purpose and goals. Pausing to think and reflect is good practice and can help an organisation make small changes, to avoid allowing problems to develop, or missing opportunities. In this way it is possible to build up a picture of change and progress, helping the organisation to plan into the longer term. 'Outcomes' are usually a key topic for evaluation; monitoring data collected can inform such an evaluation.

Recording guide: This information can be gathered via stakeholder workshops, interviews or surveys to investigate the views of people working with the organisation, affected by the organisation. It is also important to seek the views of people in organisations which the organisation aims to influence, e.g. mainstream service providers and funders. The information might be recorded in reports.

- Sustainability progress on qualities that support organisation's sustainability, e.g.
 - Changes to organisation's purpose, structure or strategies and reasons for these changes
 - o Organisation learning from experience, and developing
 - o Ongoing balance of resources, supports and CBR activities
 - o Expansion of program(s) and reach, depending on demands and resources
 - Adaptation to local context and information from experience
 - o Communication within organisation
 - Networks and community linkages (quality of)
 - Networks of external partners (e.g. on funding, equipment, capacity building)
 - Referral arrangements
 - Access for participants to referral services (distance, cost)
 - Referrals to CBR organisation from community and other services
 - Linkages with community, government etc.
 - Links with mainstream services
 - Feedback from stakeholders
 - Public participation
 - Dedication of participants.

• Environmental strengths e.g.

- o Policy strengths (e.g. health, education, employment, transport)
- Changes to the organisation's environment (e.g. policy or legal changes affecting the organisation)
- Increased participation by PWD including women, in policy roles in the community
- o Community understanding of disability and discrimination.

ACTIVITIES

This group of items relates to the activities of an organisation which aim to improve the situation of their participants, their participants' families and/or the communities in which they operate. There are two categories of items: those relating to what is done and those relating to outcomes of the activities.

The range of activities would usually be the activities over which the organisation has some control or responsibility. Other activities that affect the environment of the organisation or the environment of their participants would be recorded as environmental facilitators or barriers in items O3 or P3.

A1 - Activities: what is done

Definition: Actions taken by an organisation and stakeholders that are intended to serve participant goals through direct interaction with participant, family or community. **Significance and use**: Items in this group may provide a picture of what organisations or stakeholders are actually doing – the main activities, including the services provided, and the planning, preparation and management activities undertaken. An accurate description of what is being done allows tracking of links between goals (of the organisation – e.g. item O1.1; of the person e.g. P2) and outcomes.

This information can be used to contribute to NGO and government reports to the UN on the implementation of the UNCRPD.

Recording guides are provided for each of the three topics suggested for this category: planning and management activities (A1.1) and then two more topics focussed on different targets: people and families (A1.2) and the community more broadly (A1.3).

As a general principle it is important to record not only what the program intends to deliver, but what is actually provided. Methods of recording what is provided will vary according to the type of activity and the counting method that is most relevant to the organisation, e.g. equipment provided to a participant, visit made to a participant, vocational program provided to a participant, amount of micro-credit loan provided. If these records are made for each participant they can then be turned into numbers of activities (statistics) across the organisations.

A 1.1 Planning and managing activities

Definition: Actions undertaken by the organisation, its staff (including volunteers) and stakeholders to plan and manage organisational activities.

Significance and use: Documentation of planning and management activities can be an important responsibility and can assist in reporting to stakeholders. Documentation can also help to promote good methods by increasing awareness of the importance of planning and management activities to support quality service provision. For instance, a Disabled People's Organisation (DPO) may be involved in advocacy and also provide counselling services; they may wish to plan these activities separately, to avoid confusion, but may also wish to consider the possible inter-relationship (e.g. to consider separation of roles, cross-referral, mutual learning). Documentation enables monitoring (periodic review) of the appropriateness of these processes, to achieve the organisation's goals.

Recording guide: Recording relevant information may involve listing the planning and management activities undertaken. Brief accompanying information could also be recorded, e.g. when the activities are carried out (e.g., during establishment phase; continuously; monthly), and methods used (e.g., collecting data on paper or using a computer). Information on planning and management activities may be collected for the organisation as a whole, or for each different service type. The information may be described in terms of:

• Planning and preparing services, e.g.

- Document goals and objectives
- Outline & describe services
- Prepare communication strategies
- o Consult with participants and families
- o Prepare community/awareness raising
- Define processes and responsibilities
- Plan participation for program participants and families
- Organise service settings
- o Transfer skills to staff/volunteers
- o Plan and obtain materials, equipment, medicines
- Plan record keeping
- o Identify other important services (e.g. mainstream services, traditional healers).

• Managing services, e.g.

- Monitor and evaluate
- o Collect data, including baseline data
- o Communication and information dissemination
- o Fund raising.

A1.2 Activities targeting people and families

Definition: A description of the different types of activities and services of the organisation targeted to people and families.

Significance and possible use: This information could be used to:

- · explain the link between goals and activities
- monitor changes in the service mix over time,
- compare with other local organisations (i.e. working with the same community or participant population), or
- compare with organisations in other places (e.g., to identify similar organisations with which informative comparisons might be drawn).

Services delivered may also be recorded for individual participants, as a record of which services a client has used. At an organisation level this would provide a basis for looking at the number and characteristics of participants who have accessed different services.

Recording guide: The following broad service types are suggested, with examples, as a basis for listing services provided. More detailed descriptions of services could also be recorded.

• Health promotion, e.g.

- Bed nets to prevent malaria
- Therapy, e.g.
 - Individual therapy sessions

- Home exercise programs
- Counselling, e.g.
 - Social or supportive counselling
 - Giving moral support (respecting dignity and understanding problems)
- Financial aid, e.g.
 - Arrange financial aid;
 - Provide microcredit or loan; provide funding or loan to start business after training, or purchase equipment e.g. sewing machine
- Equipment, assistive devices (and associated training), e.g.
 - o Provide assistive devices and equipment (e.g. hearing aids, white canes)
 - o Maintain assistive devices and equipment
 - o Provide training in equipment use
- Education and skills development (person), e.g.
 - o Advice on health and rehabilitation
 - o Practical daily living skills training
 - Vocational training
 - o Braille training
 - Mobility training
 - Sign language classes
 - o Empowering participants towards self-management and decision;
 - Self-help groups; focus on ability; personal development; empowerment workshops for people with disabilities and families
 - Empowering participants towards self-management and decision making
- **Support in participation**: Provide support to a person in any area of Activities or Participation (see Item P2.2 Activities and Participation), e.g.
 - o Arrange and provide support for people in vocational training
 - Provide ongoing job support for people in mainstream employment
 - Help with care and activities in the home
- · Education and skills development (family), e.g.
 - Organize parental support networks
 - Teach the family how to work with the child on goals that are of concern to family and child
 - Educate family about basic rehabilitation
 - Train and encourage the family / parents
 - Parent-driven community centres for skills training for children with intellectual disability
 - o Empowerment workshops involving people with disabilities and their families.

A1.3 Activities targeting the community

Definition: A broad description of the different types of activities and services provided by the organisation at community level

Significance and possible use: This information could be used to characterise the organisation in terms of activities and services provided, so that the organisation can, e.g.

Monitor changes in its range of services over time

- Compare services with those of other local organisations (i.e. working with the same community/participant population), or
- Compare with organisations in other places (e.g., to identify similar organisations with which informative comparisons might be drawn).

Recording guide: The following service types are suggested, with examples, as a basis for listing services provided. More detailed descriptions of activities could be recorded if needed, e.g. details of how community education was done. You might also decide to add extra information about the particular activities or services provided. For example, if you are recording that you provide special resources to schools (listed under 'Improving access to mainstream services' below) you might also decide to record the number of times special resources are provided to schools. If you are supporting self-help groups you might wish to record the number of self-help groups you are supporting or their total membership.

• Education and empowerment —community and groups, e.g.:

- Link with and educate community and groups
- Establish or support DPOs or self-help groups
- Networking, promoting community linkages
- Awareness raising among community, media, opinion leaders etc. (e.g. celebrating International Day of People with Disability); Exposure of role models (e.g. persons with disabilities, who are seen to be socially or materially 'successful')
- Advocating access to services
- Organising community events/social events
- Discussion and information dissemination at community meetings
- Use of media to promote the needs of people with disabilities
- Working to change community attitudes

• Improving access to mainstream services: e.g.

- Promoting inclusion in mainstream schools
- Teaching school staff about disability, training in supports including basic rehabilitation needs and techniques
- Talking with workers in local health clinics and other health workers
- Help people access mainstream services (e.g. health, education, medical treatment such as surgery)
- o Remove/reduce environmental barriers to mainstream services
- o Providing or lending special resources to mainstream services (e.g. schools)
- Providing transport (e.g. for referrals)
- Adapting facilities to remove/minimize environmental barriers
- Promoting/advocating access to services

A2 Activity outcomes

Definition: The quality of and accomplishments from the activities of the organisation, judged against organisational purpose

Significance and possible use: This group of topics may assist the organisation to reflect on its activities and find ways to improve their quality and effectiveness, e.g. by identifying potential problems or opportunities and adjusting practice. Periodically pausing to think and reflect is good practice, and can help an organisation make small changes to avoid problems

developing or missing opportunities. 'Outcomes' is usually a key topic in evaluation; monitoring data collected can help evaluation.

Recording guide: Summarising outcomes can be done periodically, to review progress and how the organisation's activities are done and whether they result in goals being achieved. This information can be gathered from stakeholders (e.g. participants, people working with the organisation) in workshops, interviews or surveys. The topics below can be talking points in workshops, and in interview guides. Later, the information might be recorded in reports (e.g. with findings and recommendations); over time it can build up a picture of change and progress.

Note: Service outcomes could be investigated at the same time as organisation outcomes, if similar groups of people are involved in discussions or interviews. [Otherwise the two investigations should be separated so as not to over-burden stakeholders.]

How are services regarded? e.g.

- o Participants and families recommend services to others
- o Services are used as a model by other organisations developing new services
- Participant views are positive ('satisfaction')
- o Participant commitment to be involved in program sustainability
- Service can mobilise local support and funding community enthusiasm and commitment
- Commitment from DPOs and NGOs
- o Government support

• Do services adhere to CBR principles, and are they locally appropriate? e.g.

- Participatory processes in delivery of CBR (e.g. involvement of people with disabilities in program)
- o CBR model adapted to local conditions, values and culture (including indigenous)
- Participants can influence services
- Equality of access to programs (e.g. for men and women)

• What did the activities accomplish? e.g.

- o Participants have greater confidence that their human rights will be upheld
- Economic benefits for participants (e.g., new businesses started and maintained; improved income after training)
- Child/participant more confident in participating in mainstream services and activities
- Participants and family are empowered (e.g. do not wait for CBR worker to administer basic services)
- o Parental pride: in child's achievements, in own ability to influence other parents
- Accessibility to services improved
- o Reduced stigma; increased equality; greater inclusion
- Influence on health, rehabilitation and equipment services (e.g., school staff learning sign language)
- o Influence on government, e.g. policy change
- Services collaborate and have good relationships with other organisations

WORKFORCE

The items in the Workforce group relate to people employed by the organisation, either paid or unpaid: these are people for whom the organisation has some responsibility. They are working towards the goals of participants and the organisation, generally on the activities outlined in the group of items relating to Activities.

Definition: The workforce comprises all people employed by the organisation, both paid and unpaid; the organisation may want to separate these two groups in its records. The term 'workforce' suggests some form of contract or agreement about the responsibilities of and tasks to be performed by the person, including for unpaid staff.

Significance and use: Many organisations want to profile their workforce, in terms of their roles, experience and qualifications, and may wish to review their performance in relation to the organisation's purpose and values. Suitable items may enable organisations to review resources, training needs and staff shortages. The items listed here relate to monitoring overall. Staff records for administrative purposes (e.g. pay arrangements, holiday leave) are not considered here and would be additional in any information system.

Recording guides: Provided below with items.

W1 Personal profile of staff

Volunteer or paid staff

Can be recorded in words or using abbreviations. Using a code such as 1.Paid staff; 2 Volunteer (unpaid) staff e.g. assists with compiling statistics if using computer records (this may include people receiving some funding to cover expenses)

- Gender
 - Definition: Whether the person is male or female.
 - Significance and recording: This concept is applied if data needs to be categorised by sex. The concept is in general coded, i.e. represented through a code list. A commonly used code list is: 1. Male; 2 Female 3. Other or unspecified (see P1.5)
- Disability: whether person identifies as a person with disability
- Payment to staff
 - It is usual to show the currency (e.g. dollars), a number (e.g. 20), the relevant time (e.g. one week); that is, remuneration of \$20 per week
- Qualifications and experiences
 - All qualifications and experiences of the staff member can be recorded as words or, if needed, the organisation can work out codes for common qualifications [See ISCED2011 for codes for qualification level and broad content
 - http://www.uis.unesco.org/Education/Pages/international-standard-classification-of-education.aspx]
- Date of entry and exit
 - Recorded in the usual way e.g. day, month, year. The dates would generally relate to the period in which the person had a contract or arrangements to fulfil a particular role for the organisation.

W2 Knowledge and skills of workforce

Definition: The information, understanding and ability of the workforce, relevant to the organisation's purpose and activities and the participants' needs.

Significance and possible use: A periodic review of a staff member's knowledge and skills is one part of ongoing service monitoring and improvement. Usually the purpose of review is to identify areas where further staff training would be of value to the staff member and to the organisation.

Recording guide: The following examples of types of knowledge and skills may assist in thinking about what to evaluate (there may also be other important information items). The information – and the plan for more training – would usually be recorded in words, following a discussion between the staff member and a supervisor.

- Understanding the aims and methods of rehabilitation
- Goal writing and plan development
- Training skills (e.g. ability to train volunteers, staff)
- Participant training and support
- · Staff supervision
- · Report writing
- · Book keeping
- · Basic anatomy
- · Mobilising the community
- · Managing rehabilitation programs.

W3 Responsibilities of staff/volunteers

Definition: The duties and obligations of staff/volunteers and the areas of work they do to meet these obligations

Significance and possible use: It is essential for staff members to know what their responsibilities are. Equally, it is important for an organisation monitoring its own performance to see how well staff roles and responsibilities match with the organisation's purpose and its service provision activities. The staff tasks that are actually carried out may develop over time, in response to new needs in the community, and it is important for people in the organisation to know about this.

Recording guide: Responsibilities and areas of work are usually agreed in employment contracts and arrangements with volunteers. However they may change over time in response to new needs in the community. The following are examples of types of responsibilities and tasks:

- Educate the community
- Getting the community involved
- · Identify and be sensitive to need
- Recruitment of village captains
- · Training and education of, e.g.
 - o Staff
 - Volunteers
 - People with disability
 - Family

- o Community/community group
- o Referral
- · Supervision, mentoring, coaching.

W4 Training undertaken

Definition: Training is the development of specific skills, habits or attitudes **Significance and use**: Training undertaken by staff/volunteers is frequently of interest to the organisation, e.g. whether staff have been provided with the training and skills they need to undertake their responsibilities.

Recording guide: The following examples of types of training may assist in thinking about what to record. There may also be other relevant information items of interest to the organisation. The information would usually be recorded as text, in a designated part of the staff member's record.

- CBR philosophy, understanding of the CRPD and its implications
- · Roles and responsibilities and key mechanisms of local development
- Disability and the needs, rights and priorities of people with disabilities
- · Accessibility and reasonable accommodation
- Community development, disability inclusive development
- Basic prevention (e.g. of injury or disease)
- Disaster management and emergency response
- · Rehabilitation techniques
- Assessments (as relevant to the work of the organisation)
- · Supervision of staff or participants
- Training techniques

W5 Quality of performance of staff/volunteers

Definition: How well staff/volunteers are carrying out their responsibilities,

Significance and possible use: It is sometimes relevant to look at whether staff members are carrying out their responsibilities well.

Recording guide: Stakeholders and organisations may agree on relevant indicators of staff performance. Some suggestions are:

- Meets targets and demands
- · Quality of relationships with mainstream services
- Attitudes
- · Has the confidence of other staff/volunteers and participants
- Positive or negative impact
- · Responding to new and unforeseen demands
- · Response to supervision
- Trustworthy
- Interest in working in low resource or rural settings.