DEVELOPING THE WPR DISABILITY INCLUSIVE HEALTH AND REHABILITATION TOOL

Technical Report – November 2013

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Contents

1. Technical Report

2. References

3. Appendices

Appendices

Appendix 1   WPR Disability Inclusive Health and Rehabilitation Tool (attached PDF)

Appendix 2   Rehabilitation and Habilitation. Presentation by Prof. Gwynnyth Llewellyn, Director, Centre for Disability Research and Policy to Consultation on the Global Action Plan on Disability for WPR and SEAR, Manila, 30 - 31 October 2013.

Appendix 3   WPR Disability Inclusive Health and Rehabilitation Tool. Presentation by Prof. Gwynnyth Llewellyn to WPR Disability and Rehabilitation Programme Review and Planning, Manila, 1 November 2013.

TECHNICAL REPORT

Context

Resolution WHA 66.9 – Disability at the Sixty-sixth World Health Assembly session in May 2013 required the Director-General to develop a Global Action Plan on the health of persons with disabilities. The first draft titled *'Better health for persons with disabilities'*, became available in July 2013 and has been subject to on-line feedback and in person consultations in all WHO regions in the intervening period.

Western Pacific Regional Office of WHO is keen to establish regional baseline information about disability inclusive health and habilitation and rehabilitation services including community based rehabilitation and assistive technology. This will assist in providing a map of capacity in these areas for the region as well as a foundation on which to ascertain progress in relation to the objectives of the Global Action Plan.

To address this identified need, Terms of Reference were developed under WP-13-MHI-004419TORs titled Development of National Disability Health Inclusive Tool and Indicators in early September 2013 with a finalization date of 8th November 2013. The overall purpose of the project was to produce a mapping tool. The aim of the mapping tool is to provide:

1. Baseline information in the form of a map of disability inclusive health services, habilitation and rehabilitation, community based rehabilitation and assistive technology in the member states in WPR.

2. The means by which information could be collected in the future to determine progress in meeting the objectives of the Action Plan as per above.

3. Identification of good practices that can be shared across the region.

4. Identification of gaps where more attention may be needed to achieve progress.

Process to develop the tool

Phase 1 – February to May 2013

Development and trialling of a pro-forma for Rehabilitation Sector Situation Analysis in Lao PDR. This proforma was based on the WHO Health Systems Strengthening Framework and Key Components of a Well Functioning Health System[1]. The full report of development of this proforma and findings are available in a Report to WPRO[2]. In brief the proforma utilizes all six building blocks of the Health Systems Strengthening Framework and applies this framework to rehabilitation sector situation analysis in a national context. The proforma was trialled during a Lao PDR in-country visit by Professor Gwynnyth Llewellyn in late April- early May 2013.

Phase 2 – September to November 2013

In this phase, the proforma was reviewed and refined to meet the needs of the current project, that is, a mapping tool in survey format. In addition, terms of reference 3.1 and 3.2 were actioned by desk review. The essential criteria and content for rehabilitation, community based rehabilitation and assistive technology were sourced from multiple documents including the materials referenced at the end of this Technical Report. Telephone consultation with Dr Hasheem Mannan, Nossal Institute for Global Health, University of Melbourne, who was engaged by WPRO for a desk review on disability inclusive health and indicators, resulted in bringing all sections of the mapping tool into one document.

Following this, the initial draft of the *Disability Inclusive Health and Rehabilitation Survey* was presented to WPRO divisions by Professor Llewellyn and Dr Mannan in a series of meetings and presentation over a two day period on 5th and 6th October in Manila. Feedback from this two day working meeting, organized and coordinated by Pauline Kleinitz Technical Officer DAR/MHI, was then incorporated into a revised draft which, following several iterations, was further developed into a PDF format for further consultation.

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[1] Key Components of a Well Functioning Health System, WHO, May 2010 which builds on earlier publications including *Monitoring the Building Blocks of Health Systems: A Handbook of Indicators and Their Measurement Strategies*, WHO, Geneva, 2010

[2] Rehabilitation Sector Situation Analysis. Lao PDR April-May 2013, The Centre for Disability Research and Policy, The University of Sydney. Submitted to WPRO, May 2013.

The PDF format titled *WPR Disability Inclusive Health and Rehabilitation Tool*[3] was presented at the WPR Disability and Rehabilitation Programme Review and Planning on November 1st in Manila. The meeting was held immediately following the Consultation on the Global Action Plan on Disability for WPR and SEAR in Manila from 30th October to 1st November 2013 inclusive. Professor Llewellyn also participated in the Consultation Meeting, 30-31 October and presented on Rehabilitation and Habilitation[4]. This provided an additional opportunity to consider and discuss with participants the most appropriate content, expression, layout and formatting and process for distribution and completion of the *WPR Disability Inclusive Health and Rehabilitation Tool*.

The two hour consultation – feedback session on the *WPR Disability Inclusive Health and Rehabilitation Tool which* occurred on Friday 1 November was facilitated by Professor Gwynnyth Llewellyn with assistance from Dr Kirsty Thompson CBM Australia. The process for this session is described in the session PowerPoint (attached)[5]. In country groups, participants reviewed all sections of the mapping tool, noted comments on one copy per country and presented their comments to the whole group. This consultation session offered insightful and extremely useful feedback on comprehensiveness, acceptability, accessibility, practicality and utility of this mapping tool.

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[3] Appendix 2 WPR Disability Inclusive Health and Rehabilitation Tool prepared for WPRO by Professor Gwynnyth Llewellyn, Director, The Centre for Disability Research and Policy, The University of Sydney and Dr. Hasheem Mannan, The Nossal Institute for Global Health, The University of Melbourne.

[4] Appendix 3 Rehabilitation and Habilitation. Presentation by Prof. Gwynnyth Llewellyn, Director, Centre for Disability Research and Policy to Consultation on the Global Action Plan on Disability for WPR and SEAR, Manila, 30 - 31 October 2013.

[5] Appendix 4 WPR Disability Inclusive Health and Rehabilitation Tool. Presentation by Prof. Gwynnyth Llewellyn to WPR Disability and Rehabilitation Programme Review and Planning, Manila, 1 November 2013.

Recommendations

1. That the feedback derived from the Consultation session Friday 1 November be considered in detail for incorporation as appropriate into the existing *WPR Disability Inclusive Health and Rehabilitation Tool.*

2. That the revised tool be formatted as an internet based and paper survey and trialled in at least three countries in the region – preferably one low income, one middle income and one high income - to ensure tool compatibility with the varied situations and diverse needs of member states in WPR.

3. That further thought is given to the most appropriate means of distribution and completion of the mapping tool. Completion of the tool would ideally be achieved by a consultative process led by the WHO country focal points on disability and including disability focal points in the relevant ministries and persons with disabilities or their representative organisations. Advice on ways in which to complete the tool could also be sought in the trialling process suggested in Recommendation 2 above.

4. That the revised tool be reviewed/ considered by WHO DAR Geneva for their comment and in particular to ensure the tool is in line with the updated/ revised version of the WHO Action Plan following the recently completed consultation period.

Gwynnyth Llewellyn

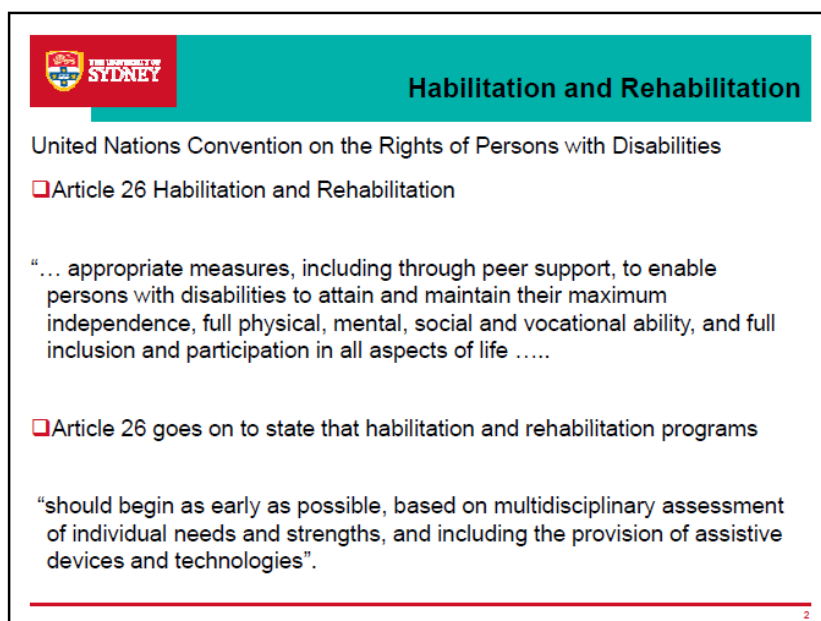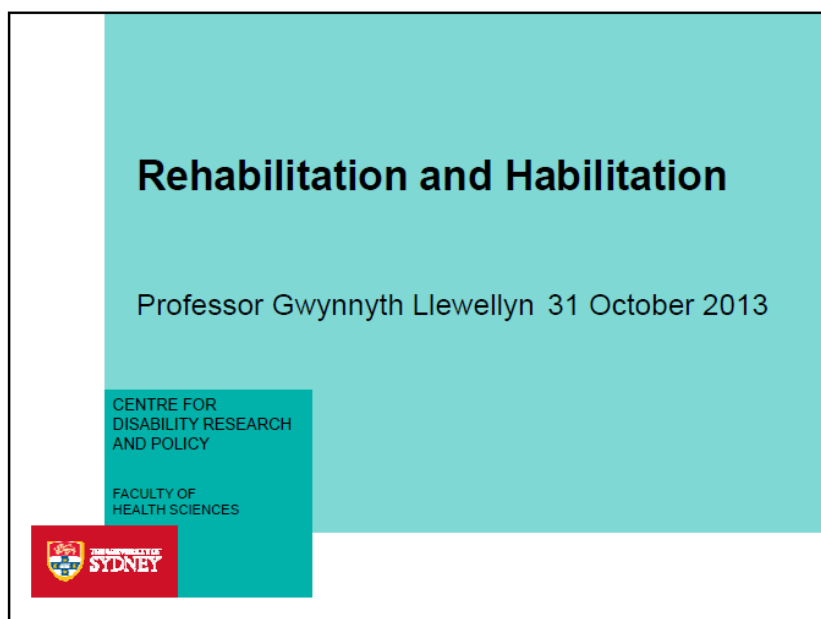Submitted by Professor Gwynnyth Llewellyn

15th November 2013

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Appendix 1 - WPR Disability Inclusive Health and Rehabilitation Tool

See attached separate file

Appendix 2 – Rehabilitation and Habilitation, Presentation by Professor Gwynnyth Llewellyn, Director, Centre for Disability Research and Policy to Consultation on the Global Action Plan on Disability for WPR and SEAR, Manila, 30-31 October.

Rehabilitation and Habilitation

Professor Gwynnyth Llewellyn 31 October 2013

CENTRE FOR
DISABILITY RESEARCH
AND POLICY

FACULTY OF
HEALTH SCIENCES

SYDNEY

SYDNEY

Habilitation and Rehabilitation

United Nations Convention on the Rights of Persons with Disabilities

❑Article 26 Habilitation and Rehabilitation

"… appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life ….."

❑Article 26 goes on to state that habilitation and rehabilitation programs

"should begin as early as possible, based on multidisciplinary assessment of individual needs and strengths, and including the provision of assistive devices and technologies".

Habilitation and Rehabilitation

World report on disability (2011)

" A set of measures that assist individuals **who experience, or are likely to experience disability** to *achieve and maintain optimal functioning in interaction with their environments*".

☐ Importantly both set out to assist individuals

to achieve and maintain optimal functioning in interaction with their environments

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Rehabilitation and habilitation

Enabling inclusion and participation

☐ Rehabilitation used as an umbrella term to also include habilitation

☐ Rehabilitation measures as defined in the *World Report on Disability*
　☐ Rehabilitation medicine
　☐ Therapy
　☐ Assistive technology

Habilitation

❑ Services that help a person learn, keep, or improve skills and functional abilities that they may not be developing normally.

❑ Habilitation refers to services for those who may not have ever developed a skill, such as a child who is not talking as expected for his or her age.

❑ For example, autism may leave a child unable to speak. Cerebral palsy may result in language deficits and severe physical limitations. Birth trauma may leave a child deaf.

❑ Children with developmental delay – early intervention

❑ Adults can also benefit from habilitation

❑ For example, adults with intellectual disability who may not have had the opportunity to learn self care skills

Habilitation

Habilitation is for those who are likely to experience disability

Rehabilitation

Rehabilitation is for those who already experience disability

Source: Cambodia Trust

Focus of rehabilitation

Achieving the best possible functioning

❑ *Prevents the loss* of function

❑ *Slows the rate of loss* of function

❑ *Improves or restores* function

❑ *Compensates for lost* function

❑ *Maintains current* function

Components of rehabilitation

Individual functioning

❑ Rehabilitation targets **individual functioning** - e.g., by remediation techniques, provision of assistive devices and technology.

Source: Handicap International

Source: University of Sydney

Components of rehabilitation

Individual's physical and family environment

❑ Rehabilitation also involves the **individual's physical and family environment**

Installing a ramp and handrails

Teaching exercises to family members

Multiple interventions

❑ Rehabilitation typically involves **multiple interventions** – e.g., physical exercises, providing prosthetic limb or assistive devices and technology, in context of work/ school and home environment.

Teaching transfers with walking frame

Source: Handicap International

Multi-disciplinary team

❑ Rehabilitation is typically carried out by a **multi-disciplinary team** – e.g., rehabilitation physician, physiotherapist, occupational therapist, speech therapist, prosthetist and orthotist

Source: University of Sydney

Source: CBM

The rehabilitation process

❑Rehabilitation involves:

❑Identifying a person's functioning difficulties and needs
❑Considering functioning difficulties in relation to the person and their environment
❑Focusing on the person's goals and their life context
❑Defining with the individual their rehabilitation goals
❑Planning and implementing rehabilitation measures
❑And, monitoring and assessing the effects of rehabilitation

Rehabilitation settings

Hospital, rehabilitation centre, community, home

❑*Hospital settings*: For example, general hospitals, rehabilitation wards within general hospitals, specialized rehabilitation hospitals.

❑*Institutional settings*: For example, rehabilitation centres, nursing homes, respite care centres, hospices, and military residential settings.

❑*Community based settings:* For example, single or multi-professional practices (office or clinic), homes, schools, and workplaces.

❑*Community based rehabilitation*: For example, at village or local level in the community

Rehabilitation services

Delivered in different ways

❑ *Inpatient*

❑ *Outpatient*: includes day rehabilitation

❑ *Outreach*: in a community setting, or at home and including mobile and tele-rehabilitation

❑ A reminder that most people with disabilities require fairly low cost, modest rehabilitation and related services that can be providing in primary and secondary health-care settings or in the community

15

Rehabilitation outcomes

Benefits and changes in functioning

❑ Increased Independence

❑ Increased contribution in family life

❑ Decreased caregiving demands on family members

❑ Return to school or going to school for the first time

❑ Return to work or being employed for the first time

❑ Improved quality of life

❑ Fewer hospital admissions and need for specialist services

16

Best practice in rehabilitation

Components of best practice
- ❑ National level commitment – legislation and/or policy
- ❑ National rehabilitation plan
- ❑ Lead agency on rehabilitation
- ❑ Quality standards in rehabilitation
- ❑ Accessible, affordable rehabilitation services
- ❑ Multiple settings: hospital (tertiary), hospital (provincial) rehabilitation centre, CBR
- ❑ Effective rehabilitation workforce
- ❑ Always involving participation of people with disabilities in planning and evaluation of services

(WHO, 2011; American Academy of Physical Medicine and Rehabilitation,2011; Australian Rehabilitation Alliance, 2011; Royal College of Physicians & British Society of Rehabilitation Medicine, 2011; Nancarrow, 2009; New & Poulos, 2008; Gutenbrunner et al., 2007; Wade, 2000)
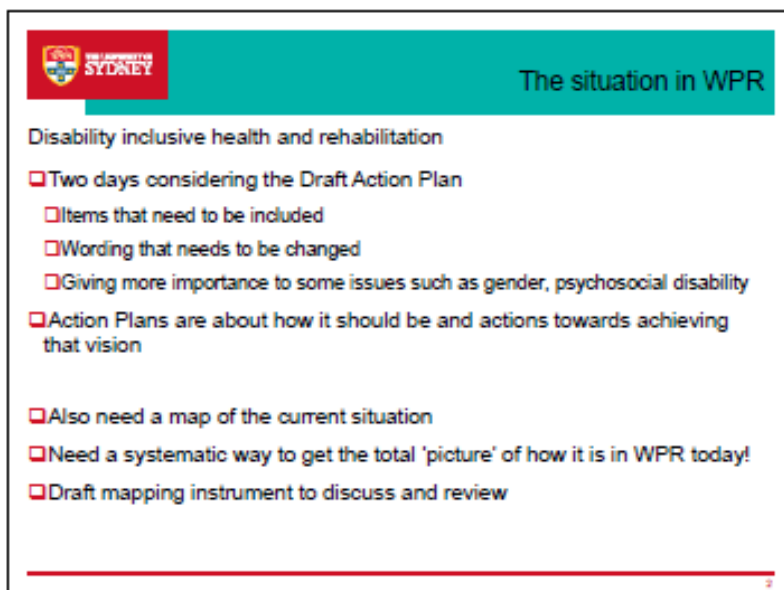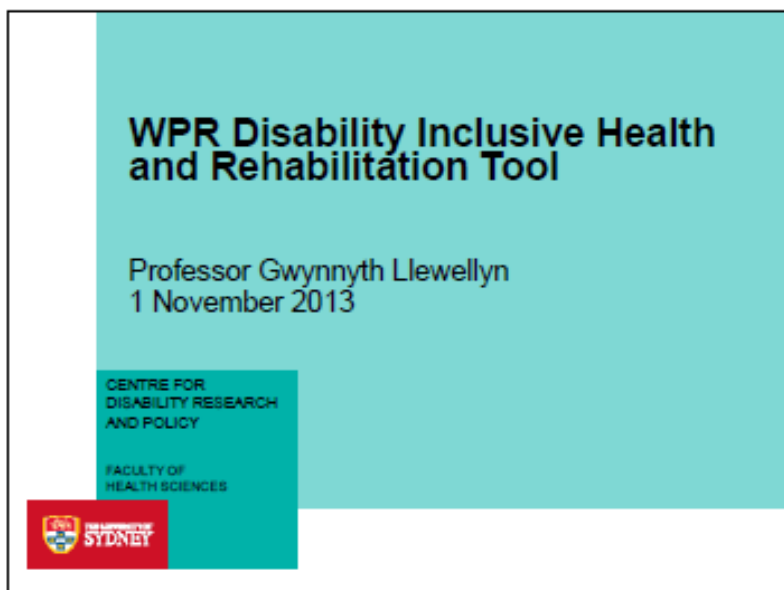

Thank you for your attention

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Appendix 3 WPR Disability Inclusive Health and Rehabilitation Tool.
Presentation by Professor Gwynnyth Llewellyn to WPR Disability and
Rehabilitation Programme Review and Planning, Manila, 1 November 2013.

The WPR tool – a mapping instrument

Aim

❑ To map the current situation in WPR on disability inclusive health and rehabilitation

❑ Why?

   ❑ To have information and a record on the current situation across the region

   ❑ To be able to see how the situation progresses over the time of implementation of the Action Plan

   ❑ To identify areas where there are good practices that can be shared across the region

   ❑ To identify gaps where more attention may need to be given to achieving progress

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Conceptual and organization frame

WHO Strengthening Health Systems

❑ 6 Building Blocks in this model

   ❑ Leadership and governance

   ❑ Financing

   ❑ Information systems

   ❑ Service delivery

   ❑ Workforce

   ❑ Technology

❑ Rehabilitation essentials

   ❑ From desk review

   ❑ WHO Guidelines on Health-Related Rehabilitation

❑ Mapping approaches

Focus of the mapping instrument

❑Mainstream health care for people with disabilities

❑Rehabilitation services

❑Community based rehabilitation

❑Assistive technology

Mapping instrument layout

Two questionnaires

❑Questionnaire 1   Mainstream health care for people with disabilities

  ❑ This questionnaire has 4 Parts

❑Questionnaire 2   Rehabilitation services, community based rehabilitation and assistive technology

  ❑This questionnaire has 7 Parts

Questionnaire 1

Mainstream health care for people with disabilities

- Part A   Governance and leadership

- Part B   Information

- Part C   Service delivery

- Part D   Health workforce

Questionnaire 2

Rehabilitation, CBR and Assistive technology

- Part A   National governance mechanisms for rehabilitation
- Part B   Financing of rehabilitation
- Part C   Information systems
- Part D   Rehabilitation service delivery
- Part E   Rehabilitation workforce
- Part F   Community based rehabilitation
- Part G   Assistive technology

Design and layout

Question types and the reasons

❑ Yes/ No questions – on 'facts' – exists or does not
  ❑ If yes, please describe

❑ Scale questions – on degree of presence of the item
  ❑ Not at all
  ❑ Sometimes
  ❑ Most of the time
    ❑ If answering sometimes, most of the time, please describe

❑ Rating scale questions – proportion in relation to item
❑ List questions – name all that are available

Questions now as we review the draft

Overall questions

❑ Is the content comprehensive in each of the questionnaires?

❑ Is the content in each questionnaire easily understood?

❑ Will the questions in each section be understood by the focal point on disability?

❑ Will the focal point on disability be able to understand these questions?
  ❑ If not, what other person/ persons would you suggest?

Second level of questions

Detailed questions about each Part of the two questionnaires

❑Is each question clear and easily understood?

  ❑List the questions where you do not know what they mean?

❑Is the answer format clear and easily understood?

  ❑List the questions where you do not understand how to answer the question

❑Can the questions be answered?

  ❑List the questions where you do not know how to get the information to answer the question

11

Questionnaire 1

Mainstream health care for people with disabilities

❑Part A   Governance and leadership

❑Part B   Information

❑Part C   Service delivery

❑Part D   Health workforce

12

Overall Questions

☐ Is the content comprehensive?

☐ Is the content easily understood?

☐ Will the questions in each Part be understood by the focal point on disability?

☐ Will the focal point on disability be able to understand these questions?

   ☐ If not, what other person/ persons would you suggest?

Second level questions

For each Part of the questionnaire

☐ Is each question clear and easily understood?

   ☐ List the questions where you do not know what they mean?

☐ Is the answer format clear and easily understood?

   ☐ List the questions where you do not understand how to answer the question

☐ Can the questions be answered?

   ☐ List the questions where you do not know how to get the information to answer the question

Questionnaire 2

☐ Part A   National governance mechanisms for rehabilitation

☐ Part B   Financing of rehabilitation

☐ Part C   Information systems

☐ Part D   Rehabilitation service delivery

☐ Part E   Rehabilitation workforce

☐ Part F   Community based rehabilitation

☐ Part G   Assistive technology

Overall Questions

☐ Is the content comprehensive?

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Second level of questions

For each Part of the questionnaire

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❑ Is the answer format clear and easily understood?

  ❑ List the questions where you do not understand how to answer the question

❑ Can the questions be answered?

  ❑ List the questions where you do not know how to get the information to answer the question