Third Meeting Washington Group on Disability Statistics (WG), 19 – 20 February 2004, Brussels, Belgium

Joint commentary prepared for the third meeting of Washington City Group on Disability Statistics

Australian Bureau of Statistics (ABS) and Australian Institute of Health and Welfare (AIHW)

Unfortunately, due to a number of reasons, Australia will not be sending representatives to the meeting. However, we remain very interested in the work of the group. We hope that the meeting is productive and that an action oriented path forward is possible. This commentary outlines our views on some issues related to the meeting agenda.

Purpose

Our main concern is how to move quickly on the development of a small set(s) of questions as a general disability measure(s) for censuses and sample based national surveys, which is the main purpose of the group. Given that there are multiple purposes for the use of a general measure(s) of disability, it is necessary, in developing the measures, to focus on one or two specific purposes.

Two specific purposes are important for the general disability measure: to inform the need for services and assistance for people with a disability; and to facilitate disability prevention. It has been agreed in the first meeting that an initial focus for an internationally comparable general indicator should be the activity dimension of the ICF.

In the Australian population disability survey, the measurement of need for assistance with activities of self-care, mobility and communication were used as the broad indicators of need for services. These measures focus on the activity dimension of disability and generate disability statistics on the more severe disability population, which is the disability component of most interest to policy planners and service funders/providers.

Australian experience also shows that it is important and also feasible to collect disability data on need for services using a set of survey questions on activities. AIHW produced a number of key estimates of need for services that were used to inform policy decisions in Australia. The preparation of these estimates relied crucially on a number of disability data items indicating the need for services. The data were collected both in administrative collections and in the national population disability survey, conducted by the Australian Bureau of Statistics (ABS).

The Australian Census Advisory Group on Disability has also recommended that the questions on need for assistance with activities in self-care, mobility and communication be the first priority for consideration to be used in the Australian 2006 population census. The existing Australian disability data show that the reported prevalence of severe or profound disability (measured using need for assistance with activities of self-care, mobility and communication) is more stable and less likely to be affected by changes in perceptions and attitudes towards disability than less severe disability (AIHW 1997). Analysis of US data also found that there is no significant change in prevalence for people with more severe disability — need for help with personal care activities (Schoeni et al. 2001). Hence, focus on severe disability in the general measure of disability may increase the comparability of data from different countries.

Australian experience with disability survey, module and census approaches has shown that with each successive shortening of the number of questions used to identify disability, or a disability sub-set, the population obtained differs, but can be related if careful question design is used.

Careful consideration of the data needs/uses of Third World as well as developed countries will be required in determining if this approach could be suitable.

Governance

The governance proposals are generally sound and comprehensive, however, a few key points:

We need to ensure that well-recognised international organisations such as OECD are being involved in the work of this group. It is also important that representatives of people with a disability should be included in the development of indicators, as was agreed in the first meeting.

It would also be of benefit if member statistical agencies were expected to liaise with relevant policy departments and other key players in their respective countries. This would ensure input of views from a broader perspective, and assist in ensuring policy relevance of proposed questions.

Item 2 of the Operating Principles A, Content of Annual General Meetings (AGMs) states that major work topics for the following year and future years will be identified at the annual meeting. However, to help generate momentum we see that it would be useful if the Steering Committee could take a leading role in putting forward a suggested work program via discussion papers circulated prior to the meetings. As such it is recommended that the current list of responsibilities of the Steering Committee be extended to include the preparation of a work program strategy papers (or strategy review papers) for member review prior to AGM meetings.

We see that an initial paper would include a vision statement (drawing on established WCG meeting decisions/priorities) along with the list of favoured projects that might be undertaken to meet that end. A major benefit of such an approach is that it provides a basis determining how particular projects might best be allocated among working groups. It naturally also provides participants with the opportunity of considering how they (and their sponsoring agencies) might best contribute to particular projects before they arrive at the meeting.

The AGM could then be used to collectively review and endorse the overall strategy, clarify and confirm member interests in undertaking particular projects and, of course, progressively review the outcomes of work being doing by the various workgroups as the work develops. Resources allowing we see that it would be extremely useful to have such a paper prepared for discussion at the next AGM. Indeed if there were opportunity it would be ideal if members could respond with comments/suggestions on an initial draft of such a work program strategy paper so that the meeting could review those comments/suggestions in totality.

We also recommend the governance proposal makes reference to the need for a review (or reviews) of the overall progress of the work as a basis for validating the ongoing need for the groups continued operation. Such a review (conducted at a minimum of three to four years) would provide a useful opportunity for member countries to assess their ongoing commitments to the work of the WCG.

References

Australian Institute of Health and Welfare (AIHW) 1997. Australia's welfare 1997. Canberra: AIHW.

Schoeni R, Freedman V & Wallace R 2001. Persistent, consistent, widespread, and robust? Another look at recent trends in old-aged disability. Journal of Gerontology: Social Sciences 56B(4):S206–218.

