Groups often omitted from national, household surveys: implications for disability statistics.

Which groups are often omitted?

In most counties, the vast majority of the population, over 98%, live in private households. Therefore, for strategic, logistical and economic reasons, national surveys aim primarily to gather data on this population. Therefore, in many counties, residents living in institutions are excluded from national surveys, for example, those residing in:

- Prisons
- Residential care homes for the elderly
- Nursing homes
- Educational establishments
- Military establishments
- Workers' hostels
- Hotels

Other groups often omitted from national surveys are:

- Homeless and roofless people
- Remote groups

Why are these groups omitted?

There are several, not necessarily mutually exclusive reasons why these groups are excluded.

Size of the population

In many countries, residents of institutions comprise between one and two percent of the population and therefore it may not seem a huge loss to omit them from national surveys. Even if a sample of institutional residents was included, the national prevalence of disability among men and women of all ages would increase by a small amount.

Sampling reasons

Institutions may not be on the sampling frame used to draw samples for household surveys. Even if institutions were selected from a series of different sampling frames, the number of residents can vary in size from five to five hundred, thus to draw a sample one needs a list of all those resident there. This may involve going through confidential files.

There is also a major difficulty in distinguishing bewteen those who are permanent residents of institutions and those who are there on a temporary basis. A woman in hospital to have a baby, a prisoner on remand for four weeks, or someone staying in a workers' hostel for two months while employed far away from home can be regarded as staying temporarily in their present accommodation. Therefore if

institutions are included in the survey, care has to be taken that people are not double-counted as well as omitted.

Health of the population

In many counties, the majority of institutional residents tend to be elderly or have a health problem. Lay interviews asking questions on disability may not be so welcome in institutions that are delivering care. Many elderly residents may have memory and concentration problems. This begs the question whether residents can give informed consent to be interviewed. Even if they can give informed consent, their understanding of the questions may be variable. Such issues pose a greater challenge for interviewers in terms of the administartion of the questionniare and the recording of responsers.

Economic reasons

Although it may seem less expensive to interview residents of institutions – they are all in the same place hence reducing the number of calls to the address and they can not pretend not to be there – there is a not an inconsiderable cost in arranging the interview. Sampling residents may be a laborious and time consuming task
Getting access to institutional residents can involve a complicated process of negotiating access which can be time-consuming. It may also be necessary to get clerance from regional or local administrators, the head of the institution itself and various staff within the institution.

It is extremely expensive to send informants to the remote parts of a country. These areas are, by their very nature, sparsely populated so it is not cost effective to send interviewers there for one or two interviews. The cost can be obviated by over-sampling in these areas.

Logistical reasons

Interviewing a resident of an institution will nearly always involve contact with the person responsible for the care and well-being of that individual. This can put an extra burden on staff who are often overstretched in just performing their regular duties.

Applicability of questionnaire

Questions asked of the private household population may not be applicable to certain institutional residents. Several activities may be done for the resident, not because they can not do them but because it is more convenient for the running of the establishment that they are done by someone else, eg preparing meals or dealing with financial matters. In certain sorts of institutions, residents may not be allowed out and this may distort answers to some questions.

With the adoption of the International Classification of Functioning (ICF) the measurement of disability needs to take account of the individuals activities, participation and the environment. Institutional charactersitics can be seen as environmental barriers to functioning and participation but they are different in nature

to those which apply to the non-institutional sample. They are more correctly seen as contraints or rules imposed by the institution for the benefit or safety of residents.

Administration of the questionnaire

National surveys can be carried out with face-to face interviews, by post or by telephone. Irrespective of the relative advantages and disadvantages of each mode of administration, the choice of method is curtailed within the institutional environment.

Proxy informants

Whereas a family member may act as a proxy informant in a household survery, this is unlikely to be the case in an institutional setting.

Why is it important to cover these often excluded groups in health interview surveys?

Service provision and allocation of resources

The rationale for a national survey of disability among the institutionalised population is exactly the same as that for a private household population survey. In order to plan services effectively, it is necessary to know how many disabled people there are and how far their needs for treatment are being met. The extent of the morbid population needs to be known so that the resources and planning can effectively take this into account. The institutional population may be a very small percentage of the total population but those living in hospitals, nursing homes are likely to be extensive users of health and social services and the vast majority of homeless people need to be in contact with health services.

Social inclusion or integration

Many governments have policies directed at the integration of disabled people into society. It is important that data are collected on disabled people living in different settings – households and institutions. It can be argued that certain sections of society are doubly penalised if they are disabled and belong to what are commonly regarded as socially excluded groups, eg homeless and roofless people, low income people sharing accommodation, remote communities.

Health monitoring of the total population.

In order to provide health, social, educational or vocational services to those in need and to increase their participation in society, there is a need, however difficult it may be operationally, to collect health data on the total population – those living in private household and residents of institutions.

What is the best way of increasing coverage?

There are several approaches to increasing the knowledge base about the prevalence of disability among residents of institutions.

Census

In most countries, the national census covers both the household and the institutional population. Therefore, the inclusion of a question or even better two or three questions on disability may provide the only data on this topic covering the total population. On the downside, censuses normally take place every ten years and one may want the collection of disability data on the total population on a more regular basis.

Extending the coverage of national household surveys.

Adding an institutional element to a national survey is a very attractive option. Carring out the household and the institutional survey at the same time may be advantageoues in that the data from the two survey can be added together. However, this is a resource-hungry endeavour and it may be preferable to stagger the data collection.

Any empirical evidence, lessons learnt

Several countries have carried out large, national surveys of disability among their institutionalised populations. The most comprehemsive studies have been done in Australia, Canada, France and the United Kingdom.

Australia
Australian Bureau of Statistics, (1998) *Disability, Ageing and Carers: Summary of Findings,* Table 8.

Canada
Dowler JM and Jordan-Simpson (1990) Canada's disabled population in institutions, *Health Reports,* **2(1),** 27-36.
Herber R, Dubois MF, Wolfson C, Chambers L and Cohen C (2001) Factors associated with long-term institutionalisation of old people with dementia:data from the Canadian study of Health and Aging, *J Gerontol A Biol Sci Med Sci* **56(11)**: M693-9

France
Dufour-Kippelen S and Mesrine A (2003) Les personnes âgées en institution, *Revue Française des Affaires Sociales,* **57**, 123-148.
Goillot C and Mormiche P (2001) Enquête HID en institutions de 1998 – Résultats détaillés, *INSEE Resultats – Série Démographie et Société no. 83-84, INSEE.*

United Kingdom
Martin J, Meltzer H and Elliot D (1988) *OPCS Surveys of Disability in Great Britain, Report 1, The prevalence of disability among adults,* London, HMSO

Smaller scale studies have been attempted in a state, county or region.

Bahrain
Al-Nassir F and al-Haddad MK (1999) Levels of disdability amomng the elderly in institutionalized and homebased care in Bahrain, *East Mediterranean Health Journal*, **Mar;(5)2**: 247-254

Ireland
Gannon M, Meagher D, Johnson J, Mizra H and Farren C (1995) A survey of new long-stay hospital patients in an Irish Health Board area, *Psychiatric Services* **Apr;46(4**): 394-8

Japan
Ikegami N (1982) Institutionalized and non-institutionized elderly (1982) Social science and Medicine, 16(23): 2001-8

Some countries have carried out disability surveys in certain types of institutions or of people often omitted from surveys. The following references examine the health status or disability among prisoners.

United Kingdom
Bridgwood A and Malbon G (1995) *Survey of the physical health of prisoners*, London:HMSO

Singleton N, Meltzer H, Gatward, Coid J and Deasy D (1998) *Psyciaitric morbidity among prisoners in England and Wales*, London: The Stationery Office

United States
Colsher PL, Wallace RB, Loeffelholz PL and Sales M (1992) Health status of older male prisoners: a comprehensive survey, *American Journal of Public Health*, **Jun:82(6);** 881-4

The following references relate to surveys which focus on the health status or disability among remote populations.

Thailand
Swaddiwudhipong W, Amaritchavarn V and Boonyabuncha S (1994) Prevalence of disabling conditions in a rural, northern Thai community: a survey conducted by village health communicators, *Southeast Asian Journal of Tropical Medicine and Public Health*, Mar;25(1): 45-49

United Kingdom
Kent RM, Chandler BJ and Barnes MP (2000) An epidemiological survey of the health needs of disabled people in a rural community, *Clinical Rehabilitation* **Oct;14(5):** 481-490