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Ken Black:

The elderly - additional and specific approaches taken in Australia for the Survey of Disability, Ageing and Carers

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Introduction

The purpose of this presentation is to introduce to you some of the techniques that have been used in the Australian ABS disability surveys to ensure inclusion and identification of older people (aged 60 years and over) who have a disability.

Firstly some general issues about disability and the older population:

- there is a changing age structure of the population in Australia (and the world). People aged 65 years and over form some 12% of the population in Australia, but this is projected to rise to 24% of the population by 2051.
- there are different profiles of people in the older age groups in relation to:
  - the type of medical condition(s) present
  - the type(s) of disability
  - age at onset of disability - for older people, disability is more likely to be acquired at later ages rather than at birth or in the developmental period.
  - living arrangement - relatively more likely to be: living alone; couples in a mutually supportive caring role; living in a cared accommodation setting
  - gender distribution - more women than men living into older old age. In 1998, of people aged 65 and over, 56% were women. Of people aged 85 and over, 70% were women.
- more people with an early onset disability are living into 'old age'
- there is an 'early ageing' effect of some disabling conditions
- 'generation differences' in perception of activity restrictions and health status - i.e community attitudes and stereotypes about ageing and older people.

ABS Survey of Disability Ageing and Carers

The Survey of Disability, Ageing and Carers (SDAC) is regularly conducted by the ABS. The survey collects a wide range of information on people with a disability:

- impairments and health conditions,
- severity of restriction,
- need for and receipt of assistance,
- use of aids and equipment, and
- living conditions and socioeconomic indicators in comparison with those without a disability.

To establish disability, the survey uses around fifty questions, with up to seventy further questions to establish severity of restriction. These surveys have been conducted in 1981, 1988, 1993 and 1998.

The 1998 Survey of Disability Ageing and Carers uses a broad restricting impairment approach to identify a population with disability. A responsible adult in each selected household was asked whether anyone in the household had any of seventeen impairments or restrictions (such as loss of sight or hearing, incomplete use of arms or legs, difficulty learning or understanding, or need for help or supervision in doing things because of mental illness), and about the health condition underlying the particular impairment. Ten activities were then examined for the extent to which a person was able to carry out typical daily activities. Severity of restriction was measured on the level of assistance needed, difficulty experienced or use of aids and equipment in performing specific tasks associated with daily living, in the areas of self care, mobility, (including the use of public transport), and communication. Two further areas where restricted participation was considered to disadvantage people with a disability

were employment and education.

Results

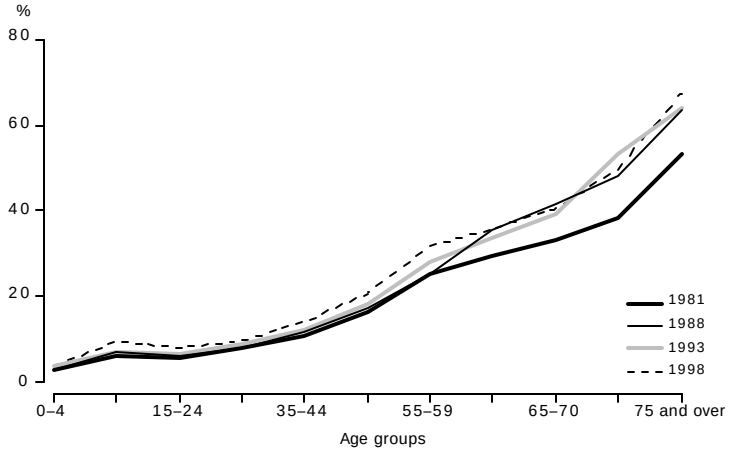
The 1998 SDAC found that 3.6 million people in Australia had a disability (19% of the total population). Of those, 87% (3.2 million) experienced specific restrictions in core activities (self care, mobility or communication), schooling or employment. The rate of disability increased with age, from 4% for children aged 0–4 years to 84% for those aged 85 years and over. A further 3.1 million had an impairment or long-term condition that did not restrict their everyday activities.

Three per cent of the population had a profound and three per cent a severe core activity restriction; the proportion with a moderate or mild core activity restriction was four per cent and six per cent respectively. While many of these were restricted in their participation in schooling and employment, a further two per cent of the population had a schooling or employment restriction only.

There has been a rise in the underlying disability rate since the first ABS disability survey in 1981. After adjusting for differences between surveys and in the age distribution of the population, the rate has increased from 15 % in 1981 to 19% in 1998. This underpins growth in the proportion with specific restrictions from 10% to 16 % in the same period. The greater part of the increase between 1993 and 1998 is for people with severe restrictions.

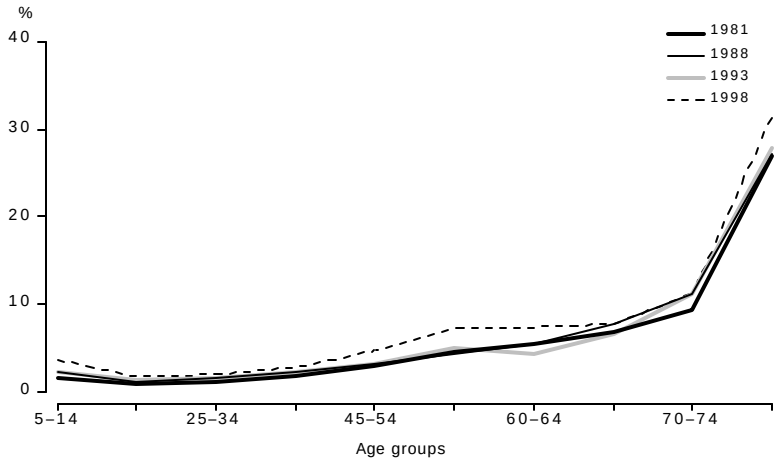
Prevalence patterns for disability by age groups show marked similarities across the four surveys (adjusted for comparability), apart from the major difference in 1981, the much lower reporting of disability by older people. With more focus on ageing in the 1988 survey, the rates among older people increased sharply. Higher rates among people aged 70 to 74 in 1993 were not repeated in 1998, but the higher concentration of people in the older part of the population aged 85 and over led to an increase in the disability rate for the highest age group.

Prevalence of disability, Australia, 1981, 1988, 1993 and 1998(a)



(a) Adjusted for differences between the surveys

Prevalence of profound/severe restriction, Australia, 1981, 1988, 1993 and 1998(a)



(a) Adjusted for differences between the surveys

The prevalence of disability has been shown to increase with age, whereas severe and profound disability remains comparatively constant until older old age is reached.

ALL PERSONS, Disability status - By Living Arrangement, Australia 1998

	SEVERITY OF DISABILITY		
	Profound or severe core activity restriction (a) %	All with disability %	No disability %
	AGED 15-64 YEARS		
Lives in a private dwelling			
- alone	6.7	14.5	6.5
- with at least one other person	80.9	82.9	92.4
Lives in a non-private dwelling			
- cared accommodation (b)	11.3	1	0
- other non-private	1	1.6	1.1
	AGED 65 YEARS AND OVER		
Lives in a private dwelling			
- alone	16.4	27.4	27.8
- with at least one other person	39	57.3	69.6
Lives in a non-private dwelling			
- cared accommodation (b)	42.8	13.2	0.5
- other non-private	1.7	2.1	2.1

(a) core activities comprise self-care, mobility and communication
(b) cared accommodation: non-private dwellings such as hospitals, homes for the aged, nursing homes, aged care hostels, disability hostels, and retirement villages (excluding independent living units).

Specific measures for the older population

Sample design

The survey was built around two components (from 1988 onwards):

1) a 'household component', which included private dwellings (houses, flats, garages, tents and other structures used as private places of residence), and 'non-private dwellings' (boarding houses, hostels, hotels, motels, caravan parks, self-care units in retirement villages etc), and

2) a 'cared accommodation component' , a separate sample drawn from non-private dwellings such as hospitals, homes for the aged, nursing homes, aged care hostels, and retirement villages with a care component.

Inclusion of non-private dwellings and cared accommodation ensured that differences in living arrangements of older people, particularly the frail aged, were taken into account - exclusion of these accommodation settings from sample design would have resulted in an undercount of older people, and in particular of older people with more severe levels of disability - data in the preceding table indicate that 42.8% of people aged 65 years or over, with a profound or severe level of core activity restriction, lived in a cared accommodation setting.

Consultation with appropriate representative groups

As part of the survey development process, a 'user group' was established to both have input into the survey content, and to advise on the appropriateness of the questions and approaches taken - included in this group were representatives of older people, such as from the 'Council on the Ageing (Australia)', 'Australian Association of Gerontology', key academic researchers, as well as from government departments with aged care responsibilities.

By taking this approach, not only was key advice and guidance received, but opportunities were available for these key representatives of people with a disability/older people and carers to discuss concerns of their constituents, and to take on some ownership of the survey - this was seen as important in ensuring maximum cooperation during the final enumeration phase of the survey.

The ABS in Australia operates under an Act of Parliament which empowers it to collect survey data, but reliance is still heavily placed on obtaining the willing cooperation of all selected respondents. Without a high response rate from all groups in the population, survey data, particularly for small sub-populations such as older people with a disability, will have little practical meaning.

Initial contact of respondents

All households selected for inclusion in the survey were sent an introductory letter (these were available in a range of languages where needed), explaining the nature of the survey, the reasons for collecting the data, the likely length of interview, and providing ABS telephone contacts for further information prior to the interviewer calling - this process is particularly important for those older people who may be frail, living alone, and hesitant about unknown callers, as well as for people who need special arrangements such as interpreters, or who are only available for interview during restricted hours.

Screening questions

A very broad screening question approach was designed to ensure that as broad a population as practical was sequenced into a personal interview to obtain details about activity restriction and participation. The screening questions were based on:

- selected impairments;
- activity limitation;
- participation; and
- key health conditions, and treatment.

The screening question set for the 1998 survey was:

- loss of sight (not corrected by glasses or contact lenses);
- loss of hearing where communication is restricted, or an aid is used;
- speech difficulties, including speech loss;
- shortness of breath or breathing difficulties causing restriction in everyday activities;
- chronic or recurrent pain or discomfort causing restriction in everyday activities;
- blackouts, fits, or loss of consciousness;
- difficulty learning or understanding things;
- incomplete use of arms or fingers;
- difficulty gripping or holding things;
- incomplete use of feet or legs;
- nervous or emotional condition causing restriction in everyday activities;
- restriction in physical activities or in doing physical work;
- disfigurement or deformity;
- mental illness or condition requiring help, or supervision;
- long-term effects of head injury, stroke or other brain damage causing restriction in everyday activities;
- receiving treatment or medication for any other long-term conditions or ailments and still restricted in everyday activities;
- any other long-term conditions resulting in a restriction in everyday activities

Note that a prompt card was used for this last question, with the following specified:

- arthritis
- asthma
- heart disease
- Alzheimer's disease
- dementia: senile and other
- any other long-term conditions not yet mentioned.

Focus groups, skirmishes and pilot testing of the survey questionnaires indicated that these screens were working effectively to identify the appropriate populations, across age groups, to take through a much more detailed set of questions by personal interview. The average time allowed by the ABS for household interviews was 45 minutes, (people with a disability and older people often taking between one and two hours), and for the next disability survey to be held in 2003, this has been reduced to 40 minutes, hence targeting and screening of population sub-groups was, and will be, critical to allow for the variety of data items required for detailed analysis by service funders, planners, providers and researchers.

Broad range of ADL's and IADL's

The Australian Society of Geriatric Medicine approved a Position Statement (No. 8) in Sept 1999, titled 'Geriatric assessment and Community Medicine'. The paper describes geriatric assessment as 'a multi-dimensional, interdisciplinary, diagnostic process used to quantify an older individual's medical, psychosocial and functional capabilities and problems....' a number of assessment scales for cognition and functional status for use in rehabilitation settings are described, however for in-home assessment (and this relates much more closely with a population survey approach) it was seen as important to obtain measures of ADL's and IADL's with the list of domains which should be included being:

- Personal activities of daily living
  mobility
  transfers
  washing/bathing including personal grooming
  dressing, including shoes and socks
  toiletting and continence
- Instrumental activities of daily living
  meal preparation
  housework
  shopping
  financial management
  transport
  medication

Draft 'UN Guidelines and Principles for the Development of Disability Statistics' also refer to the use of ADL questions as being the best method of assessing disability status among the elderly in a survey setting. ADL's (and IADL's) refer to a set of common, daily activities, performance of which is required for personal self-care and independent living. The draft guidelines also refer to the need to measure both difficulty and need for assistance with the range of activities (assistance covering both personal assistance and aids and equipment).

The first ABS survey on disability 'Handicapped Persons 1981' included a range of ADL's, and from 1988 onwards ABS disability surveys have included a range of both ADL's and IADL's. For each of the broad ADL and IADL activity areas, information was obtained on 'difficulty', 'need for assistance', 'frequency of need for assistance', and 'providers of assistance'. Data are also collected about the use of technical aids and equipment for each of the broad activity areas.

The following table details the activity areas, and the tasks within each activity, for the 1998 ABS Survey of Disability, Ageing and Carers:

Activity areas, and the tasks within each activity, for the 1998 ABS Survey of Disability, Ageing and Carers

ACTIVITY	TASKS
Communication	Understanding family/friends Being understood by family/friends Understanding strangers Being understood by strangers
Mobility	Getting into/out of bed/chair Moving about usual place of residence Moving about place away from usual residence Walking 200 metres Walking up and down stairs without a handrail Bending and picking up an object from the floor Using public transport
Self care	Showering/bathing Dressing Eating Toiletting Bladder/bowel control
Schooling	Unable to attend school Attends a special school Attends special classes at an ordinary school Needs at least one day a week off school on average Has difficulty at school
Employment	Permanently unable to work Restricted in the type of work they can/could do Need/would need at least one day a week off work on average Restricted in the number of hours they can/could work Requires special equipment/modified work environment Needs ongoing assistance/supervision Would find it difficult to change jobs/get a better job
Health care (b)	Foot care Taking medications/administering injections Dressing wounds Using medical machinery Manipulating muscles or limbs
Guidance (c)	Making friendships, interacting with others or maintaining relationships Coping with feelings or emotions Making decisions or thinking through problems
Paperwork (b)	Reading/writing tasks such as: - Checking bills/bank statements - Writing letters - Filling in forms
Transport	Going to places away from the usual place of residence
Housework (b)	Household chores such as: - Washing - Vacuuming - Dusting
Property maintenance (b)	Changing light bulbs/tap washers/car registration stickers Making minor home repairs Mowing lawns/watering/pruning shrubs/light weeding/planting Removing rubbish
Meal preparation (b)	Preparing ingredients Cooking food

(b) included from 1988 survey onwards
(c) included in 1998

The area of 'guidance' was added for the 1998 survey in recognition that psychological functioning had not been well covered by a specific question set within the body of the survey.

Interviewing in Institutions

Until 1998, the ABS disability survey 'cared accommodation' component was enumerated by interviewers, similar to the 'household' component. For 1998, as a cost saving measure, and due to difficulties in moving to the 'computer assisted interviewing' technique used in the household component for the first time in 1998, a 'mail back' questionnaire was developed for completion by administrators and staff of the selected establishments

Where interviews are used in institutions, both the interviewers and the form wording should be sensitive to the situation and to the special needs of the staff members and the respondents;

- Institution staff members (administrators or other contacts, such as head nurses and ward clerks) are busy professionals. Scheduling appointments for proxy interviews at a mutually convenient time will require flexibility on your part and organisation. Interviewers must be prepared for the fact that appointments may change with little notice.

- Interviewing respondents will also require a high degree of professionalism. You must be prepared for any situation and be able to adapt your interviewing skills to the situation quickly and tactfully. If at any time during the interview you sense that the respondent is becoming upset, or incapable of completing the interview, terminate the interview and discuss the situation with the administrator or the contact in the organisation.

Specific targeting of question sets to people aged 60 years or over, irrespective of their initial responses to 'disability' screening questions.

Extensive testing had indicated that the initial broad set of screening questions adequately identified the appropriate sub-set of the population to sequence through the detailed ADL questions relating to personal care, mobility, communication, education, employment, and health care. There were however a significant proportion of people aged 60 years or over who were not identified via the screening questions, who nevertheless had difficulty and/or needed assistance with one or more of the activity areas of paperwork, transport, housework, property maintenance and meal preparation. Based on this test data, all people aged 60 years or more were sequenced to a personal interview for the questions pertaining to these activity areas, and an additional question was asked to determine the reason for their difficulty - whether due to 'disability/health conditions', 'old age', 'doesn't know how to', or 'other' reasons. All responding to either 'disability/health condition' or 'old age' as the reason were asked further questions regarding need for help, their ability to undertake the task without help, and the frequency of need for help if help was needed.

The table following provides data on need for assistance by disability status - those people with a status of 'no disability' are those who were not identified by a positive screening question response in the initial stage of the interview, but who were sequenced through these questions due to being aged 60 years or more. Over 168,000 people (16.0%) aged 65 years and over had a 'no disability' status in standard output definition, yet had a need for help in one or more of the activity areas of transport, paperwork, housework, property maintenance, or meal preparation - and this need was due to either 'disability/health condition' or 'old age'.

OLDER PERSONS (a), Need for Assistance - by whether has a disability

	AGE GROUP.....					
	65-69 '000	70-74 '000	75-79 '000	80-84 '000	85 and over '000	Total '000
DISABILITY						
Activities for which assistance needed						
Transport	49.8	74.5	96.4	82.1	77.9	380.7
Paperwork	21	31.3	50.9	52.9	98.9	254.9
Housework	63.5	79.7	93.6	62.3	69.4	368.5
Property maintenance	108.4	130.1	120.7	79.6	75.6	514.5
Meal preparation	15.5	25.3	34.9	22.1	38.9	136.6
All needing assistance with at least one activity(b)	*156.3*	*192.5*	*192*	*155.6*	*184.1*	*880.4*
Assistance not needed	*119.3*	*108*	*78.1*	*33.2*	*6.1*	*344.8*
All persons	*275.6*	*300.5*	*270.1*	*188.8*	*190.2*	*1,225.2*
NO DISABILITY						
Activities for which assistance needed						
Transport	10.2	11.2	19.1	16.5	16.2	73.2
Paperwork	n.p.	**0.5	**0.4	*3.3	*2.8	*7.6
Housework	*4.4	9.3	*7.3	9.5	*4.8	35.5
Property maintenance	24.1	23.8	29.9	22.1	11.8	111.6
Meal preparation	n.p.	n.p.	n.p.	n.p.	*2.7	*5.5
All needing assistance with at least one activity(b)	*34.2*	*34.2*	*43.2*	*33.7*	*22.8*	*168.1*
Assistance not needed	*372*	*278.2*	*149.1*	*65.6*	*12.9*	*877.9*
All persons	*406.2*	*312.4*	*192.3*	*99.3*	*35.7*	*1,046*
TOTAL						
Activities for which assistance needed						
Transport	60.1	85.7	115.5	98.6	94.1	453.9
Paperwork	21.6	31.8	51.3	56.1	101.7	262.4
Housework	67.9	89.1	100.8	71.9	74.2	403.9
Property maintenance	132.5	153.9	150.6	101.6	87.5	626.1
Meal preparation	15.9	26.2	35.8	22.7	41.6	142.2
All needing assistance with at least one activity(b)	**190.5**	**226.6**	**235.2**	**189.3**	**206.8**	**1,048.5**
Assistance not needed	*491.4*	*386.3*	*227.2*	*98.8*	*19.2*	*1,222.8*
All persons	**681.9**	**612.9**	**462.4**	**288.1**	**226**	**2,271.2**

(a) Aged 65 years and over.
(b) Total may be less than the sum of the components as persons may need assistance with more than one activity.

Language

The words we use about people influence our attitudes, and the attitudes of others, towards those people. Words create images. Sometimes they create myths. This is certainly the case in the disability field, which abounds with labels that stem from ignorance and suspicion, and particularly when we combine the concepts of disability and old age.

It is important that the words we use are acceptable to older people. We need to be aware of the attitudes and images our words create. We should ensure that the language we use is accurate and respects the humanity of all individuals.

General Interviewing Techniques

Interviewing older people, and older people with disabilities, requires many of the same techniques as interviewing in any other statistical survey, such as a Household Labour Force Survey, a Health Survey or a General Social Survey. However, there are also some techniques that relate more specifically to interviewing older people.

ABS interviewer training is intensive, and interviewers selected to undertake surveys such as on disability are generally selected from the most experienced of the monthly labour force interviewer panel. All selected interviewers are then further trained in the specific survey: content, structure, background to the need for the data, and the specific subject matter. Where specific techniques/approaches may be required, these are identified and practiced As an example, some 'tips and traps' for interviewers:-

Interviewing older people with Disabilities - Tips and Traps

Older people are people first. React to the person, not to their age. Older people are not all alike; personal interests and qualities vary. You may get along well with some people and not so well with others; it is due to the individual and not the disability.

- Treat older people as you would treat anyone else. They do the same things as you do, but sometimes use different techniques. It is a mistake to make assumptions concerning an individual's abilities or capacities based on the appearance of his or her age/disability. For instance, many older people are very active in the community, take on volunteering roles, and travel more frequently than younger people with young family and work commitments.

- Establishing trust is vital for quality responses.

- Be sensitive to the language you use. The person being interviewed should not be made to feel like they are being labeled.

- Do not patronise older people.

- Many older people with disabilities can compensate for their disability through acquired techniques. For example, persons who have limited gripping power may utilise special equipment in the household. As such, the person may not be restricted in their own household environment

- If the person to be interviewed has an attendant or carer to accompany them, speak directly to the person wherever possible . Automatically talking to their companion promotes the image of older people being sick and incompetent, and is not conducive to a successful interview *(there are of course situations where a proxy interview is the only*

option available).

- Not all older people are ill or sick. Equating age with being ill or sick treats the person as not being responsible for himself/herself and in need of constant care.

- Never speak to an older person in a different tone of voice - meaning one that assumes difference based on ability. This creates negative feelings on the part of the person, and will likely ruin the interview.

- Maintain eye contact with the person you are interviewing. Avoiding eye contact will only increase the tension in the interview.

- Speech may be hard to understand but it does not necessarily mean a person has dementia.

- People who have unclear speech, such as some oral deaf people and people with cerebral palsy, are used to people asking them to repeat things, so be honest about not hearing or understanding everything the first time.

- People with mental disabilities may take time to understand what is being asked. There might be cases where a question will have to be explained i.e. reworded by the interviewer. Do not rush. Make sure the person clearly understands what is being asked.

- Be patient with people who are hard of hearing You may need to rephrase questions to assist their understanding. They may be anxious to please and respond to what they think they have heard, or become frustrated with continual repeating of questions.

- Fatigue may be a problem for some older people. Suggest a break as needed.

- Remember that there can be genuine need for a proxy interview in some circumstances.

Finally, some stereotypes and myths about older people in relation to disability

There are many stereotypes and myths about older people and disability. There are assumptions that older people are second class citizens and charity cases, that they are automatically not in the paid workforce, and that they are feeble minded and frail of body. Society perpetuates these myths and negative assumptions through:

- Advertising & the media
- Language
- Jokes
- Social policy
- Charities and paternalism
- Films and novels
- Fear of the unknown
- Social isolation (lack of contact with older people with disabilities)
- Physical inaccessibility
- Narrow definitions of normality

Examples of Stereotypes and Myths - older people are:

- ***Inferior and dependent* -** so they are:
  - less able than non-disabled people
  - sick and need medical care
  - helpless and can't take care of themselves
  - not capable of making their own decisions
  - not fully human

- ***Isolated and Marginalised*** - so they:
  - don't know what they need
  - would rather only associate with other older people with disabilities

- ***Child-like* - s**o they:
  - can't be caregivers
  - are asexual

- ***Not really workers* - s**o they:
  - are happy on a pension
  - can't take responsibility
  - can only do very light manual tasks
  - take more time off sick
  - don't really have career aspirations
  - don't fit the corporate image - they put off customers

- ***and of course, as for all people with a disability***
  - all people who have physical disabilities are also of low intellect
  - all people who use wheelchairs/walking frames have the same needs
  - blind people have better senses of hearing and smell
  - deaf people can't communicate
  - people with mild impairments use their disability to ignore you
  - professionals know best what's good for older people

Some other issues for consideration/discussion:

Longitudinal surveys - Canada, the United States and the United Kingdom have established longitudinal studies covering ageing issues, and Sweden is establishing a lonitudinal study *(communication from OECD meeting on the implications of disability for ageing populations, 9-10 Dec 1999)*. Longitudinal surveys can build a more complex picture of change over time, but still must be underpinned by the adequate initial identification of the population(s) of interest, hence the same consideration of screening approach applies as for one-off surveys.

Use of trained health professionals - in 1987 China conducted a national 'Survey on Persons with Disabilities' (sample size of 1.6million people), with those identified from initial contact as having a disability being followed up by trained medical practicioners for more detailed assessment. Cost and availability of trained health professionals is a significant consideration for this approach, and again, the initial screening process is critical for identification of the population for further follow-up.

Use of existing assessment tools to measure cognitive/psychological function - adequate inclusion of people with impairment of cognitive and/or psychological function is perhaps the most problematic in household surveys.
There are a number of well established, validated tools such as 'The Mini-Mental State Examination', the 'Short Portable Mental Status Questionnaire' (a 10 point scale), and the 'Iowa Dementia Test' which are useful in clinical settings, or for detailed assessment of people for program elegibility.

These tests are however relatively lengthy for inclusion in a survey (on average 5-10 minutes per person), and hence in Australia have not been included, as other important data items would have had to be excluded to accommodate them - it was felt that the very broad screening approach used in the ABS disability surveys would identify most people appropriately, particularly those screens for 'difficulty learning or understanding things', 'mental illness requiring help or supervision', 'receipt of treatment or medication for a long-term condition or ailment which still restricts the person in everyday activities' and the specific prompting for Alzheimers disease, and dementia.