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Disability and handicap among Aborigines of the Taree area of New South Wales

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Summary

Australian Aborigines and Torres Strait Islanders are known to be the least healthy identifiable sub-population in Australia, but little is known about their levels of disability and handicap.

Using an approach similar to that used by the Australian Bureau of Statistics in their surveys of the total Australian population, this study attempted a census of disabilities and handicaps among Aboriginal people living in the Taree area of New South Wales. Of the 907 Aboriginal usual residents of the Taree area included in the study, 227

Of the 907 Aboriginal usual residents of the Taree area included in the study, 227 (25.0 per cent) were identified as having one or more disabilities, 124 (13.7 per cent) as being handicapped by their disability and 46 (5.1 per cent) as being severely handicapped.

After adjustment for differences in the age structure of the two populations, the level of reported disabilities among the Aboriginal population of the Taree area was 2.5 times higher for males and 2.9 times higher for females than for males and females in the total Australian population. The levels of handicap were 1.7 times higher for males and 1.8 times higher for females, and those of severe handicap 2.4 times higher for males and 2.3 times higher for females.

The most frequently reported group of disabilities were those classified as 'disorders of the sense organs'. Nineteen per cent of all disabilities were of this type, which includes hearing loss (reported by 8.4 per cent of those surveyed) and loss of sight (1.4 per cent). 'Disorders of the musculoskeletal sytem and connective tissues' was the second most frequently reported group (16 per cent of all disabilities were of this type). The next most frequently reported groups were 'circulatory system disorders' (15 per cent of all disabilities) and 'respiratory system disorders' (13 per cent).

A mobility handicap was the most frequently reported type of handicap, with almost 10 per cent of all people surveyed reporting such a handicap. The next most frequently reported types of handicap were employment and education. For people reporting being handicapped by their disability, the most commonly reported underlying disability was a disorder of the musculoskeletal system or connective tissues, followed by mental retardation, mental degeneration due to brain damage, slow at learning and specific delays in development.

Some of the findings of this study provide the basis for immediate action, at least for the Aboriginal people included in this study, while others may require further investigation.

The high levels of disability and handicap reported by Aboriginal people living in the Taree area of New South Wales highlight the need to assess Aboriginal people living in other parts of Australia, so that appropriate action can be taken.

1 Introduction

Australian Aborigines and Torres Strait Islanders are the least healthy identifiable sub-population in Australia, with levels of mortality and morbidity much higher than those of other Australians for almost all disease categories (Thomson 1991; Australian Institute of Health and Welfare 1994).

Despite the accumulating evidence of the great disadvantages in mortality and morbidity experienced by Aborigines, ¹ little is known about the levels of disability and handicap in the Aboriginal community. Information about a number of specific diseases (derived from community surveys and levels of hospitalisation) suggests that some disabilities and handicaps are likely to be more common among Aborigines than other Australians.

There is widespread evidence, for example, of middle ear disease and associated hearing loss among Aboriginal children (Thomson 1989), but the extent to which this results in permanent hearing loss is not known. Blindness has been known for a long time to be much more common for Aboriginal people living in rural and remote areas of Australia than for other Australians (Mann 1954; Mann 1966; Royal Australian College of Ophthalmologists 1980). In its work throughout rural and remote parts of the country between 1976 and 1979, the National Trachoma and Eye Health Program found that 1.5 per cent of the 62,116 Aborigines examined had levels of vision which entitled them to a blindness invalid pension, compared with 0.2 per cent of 38,660 non-Aborigines examined (Royal Australian College of Ophthalmologists 1980). The high levels of respiratory and circulatory system disease, injury, diabetes mellitus and renal disease among Aborigines (Thomson 1989; Thomson 1991) are also likely to be associated with high levels of disability and handicap.

Despite the likelihood of higher levels of disability and handicap for Aborigines than for non-Aborigines, there have been no systematic attempts to document the actual levels experienced by Aborigines. In 1981, the International Year of Disabled People, initial planning was undertaken for a survey of disability and handicap among Aborigines, but the survey did not eventuate. No provision was made for the identification of Aborigines in the 1981 and 1988 Australia-wide surveys of disability and handicap conducted by the Australian Bureau of Statistics. Provision was made for the identification of Aborigines in the 1993 survey of disabled and aged persons conducted by the Australian Bureau of Statistics; some useful results are therefore likely to become available.

The lack of information about Aboriginal disability and handicap, and the absence of

^{1.} In this report, the term 'Aborigines' will generally be used to mean both Australian Aborigines and Torres Strait Islanders. Aboriginal identification is in accordance with the accepted 'working definition': an Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he (she) lives.

systematic efforts to collect such information, prompted the Australian Institute of Health and Welfare to consider undertaking a special survey. Following discussions with a number of Aboriginal-controlled agencies, the Biripi Aboriginal Corporation Medical Service (based in Purfleet, via Taree, New South Wales) encouraged the Institute to proceed. Biripi recognised that the information gained through such a survey would assist in planning and developing services for the Aboriginal people it served. Formal approval to undertake the survey was given by the Biripi Board of Directors and the Institute's Ethics Committee. In addition to Australian Institute of Health and Welfare resources, the survey was supported by a grant from the Australian Institute of Aboriginal and Torres Strait Islander Studies.

2 Methods

2.1 Study design

To enable the results of this study of the disabilities and handicaps of the Aborigines of the Taree area of New South Wales to be compared with information for the general Australian population, the approach used was adapted from that developed by the Australian Bureau of Statistics (ABS) for its 1988 Survey of Disabled and Aged Persons (Australian Bureau of Statistics 1990).

Based broadly on World Health Organization recommendations (WHO 1980), the ABS defined a disabled person as someone who had one or more disabilities or impairments which had lasted or were likely to last six months or more, and a handicapped person as someone whose disability limited their capacity to perform tasks in one or more functional areas. Disabilities included both mental disorders (for example, mental retardation, slowness at learning and psychosis) and physical conditions (for example, loss of sight, incomplete use of limbs or digits and long-term conditions requiring treatment or medication). The five functional areas used in assessing whether a person was handicapped by their disability were personal care, mobility, verbal communication, education and employment. (See Appendix for more detailed information about the definitions and classifications of disabilities and handicaps.)

There are two major differences between this study and the ABS survey. First, this study was confined to persons living in households, whereas the ABS survey also included persons living in health establishments and institutions. Second, this study attempted a census of disabilities and handicaps of Aboriginal people living in a limited geographic area, while the ABS survey involved multistage Australia-wide sampling of the general population living in households and health establishments.

Both this study and the ABS survey involved a two-stage collection of data. The first stage used a household screening questionnaire in which a responsible adult in each household was asked to provide simple demographic information about each person usually resident in that household and basic information about any disabling conditions of the residents.

Based on information collected in this first stage, a second questionnaire was used to collect information about those individuals identified as having one or more disabilities. This information was collected directly from the identified individuals, except where the person was aged less than 15 years, was unable to answer because of the nature of their disability, was temporarily unavailable, or had language problems. In these cases information was obtained by proxy, usually from a responsible person in the household of the person with the disability.

As well as confirming that the person did in fact have one or more disabilities, the second stage obtained a range of other information about the primary disabling condition (the condition causing the most problems, also referred to as the most

troubling condition) and whether the person was handicapped by their disability or disabilities. Children aged less than 5 years with a disability were assumed to be handicapped by their disability. As noted above, handicaps were assessed for five functional areas: personal care, mobility, verbal communication, education and employment (see Appendix). Except for children aged less than 5 years and people with an education or employment handicap, the severity of handicap was also assessed and classified as severe, moderate or mild (see Appendix).

This study attempted a total coverage of all Aboriginal people normally resident in the Taree area of New South Wales. This area includes Taree, Purfleet, Forster-Tuncurry, Cabarita, and surrounding areas. An initial list of Aboriginal residents of the area was constructed from records maintained by the Biripi Aboriginal Corporation Medical Service (based in Purfleet, about three kilometres south of Taree), supplemented by information obtained from the Taree City Council. As the study proceeded, information about other Aboriginal residents of the area was sought from persons being interviewed. In this way, it is believed that virtually all Aboriginal residents of the area were identified.

In accordance with the ethics of undertaking Aboriginal health research, the Biripi Aboriginal Corporation Medical Service actively participated in initial planning, and approval to undertake the study was given by the Service's Board of Directors. As well, the ethics of the study were endorsed by the Australian Institute of Health and Welfare's Ethics Committee. Participation in the study was also subject to individual approval, evidence of which was collected in the form of signed approval from each respondent. Most respondents also gave signed approval for access to their medical records for the purpose of clarifying uncertainties about their condition.

Field work took about seven person-weeks. Prior to commencement of interviewing, a number of local Aboriginal people were briefed about the nature of the study and some underwent training for interviewing. Conduct of the study was assisted greatly by the use of facilitators—local Aboriginal people who distributed leaflets about the survey and introduced non-Aboriginal interviewers to subjects.

2.2 Data analysis

Coded information from the questionnaires were entered into the Institute's Digital Vax computer and initial data analysis involved cross tabulations produced using Statistical Package for the Social Sciences (SPSS) release 4.1. Further analysis was undertaken using Microsoft Excel.

Grouping of the conditions largely followed the classifications used by the Australian Bureau of Statistics in its disability surveys (see Appendix). The classification of conditions for a small number of respondents involved judgements because some subjects did not provide sufficient details to enable a conclusive categorisation. In a few cases medical records were examined to provide more precise information (written permission had been given by the subject).

Crude prevalences of disabilities and handicaps provide an indication of their actual burden on the Aboriginal community, so are important in assessing the need for services, aids and assistance. Crude prevalences do not, however, provide an accurate comparison of Aboriginal and non-Aboriginal levels. Disability and handicap are strongly age-related, so comparison requires adjustment for differences in the age structures of the populations being compared. The numbers of disabilities and handicaps expected in the Aboriginal population were estimated by applying the age-specific prevalences of the total population, as documented in the 1988 Australian Bureau of Statistics Survey of Disabled and Aged Persons (ABS 1990), to the Aboriginal population (age-specific prevalences published in Mathers 1991 were used for these estimates). The age-adjusted disability and handicap ratios are the ratios of the numbers reported by the Aboriginal population to the numbers expected.

2.3 The structure of this report

To provide information for planning purposes, detailed raw data are presented in this report along with estimates summarising the crude prevalence of disabilities, handicaps, the use of aids, and the receipt of assistance. Data on disabilities and handicaps are presented in the broad groups adapted from those used by the Australian Bureau of Statistics (1990). As noted above, age-adjusted ratios are presented to provide a comparison of the relative burdens of disabilities and handicaps on Aborigines living in the Taree area of New South Wales and on the total Australian population.

Overall figures are presented for five groups of towns and communities in the Taree area:

- Purfleet (the former Aboriginal reserve community)
- Taree (includes Chatham and Cundletown as well as Taree town)
- Forster-Tuncurry (includes Pacific Palms)
- Cabarita (the former Aboriginal reserve community)
- Other (includes Old Bar, Tinonee, Wingham, Dingo Creek, Cooplacurripa, Rocks Crossing, Mt George, Lansdowne, Moorland, John's River and Purfleet Caravan Park).

The small numbers involved in this study precluded presentation and analysis of data to the extent possible in a large survey, such as the 1988 Australian Bureau of Statistics Survey of Disabled and Aged Persons (ABS 1990). Privacy considerations meant that many of the data could only be disaggregated by sex, and not also by age group.

3 Results

3.1 Aboriginal households and usual residents

Interviews were undertaken in 229 households, in which 999 people usually resided — 907 Aborigines and 92 non-Aborigines (Table 1). More than two-fifths of the households were in Taree town, with around a fifth in Purfleet and Cabarita. Almost one-quarter of the usual residents of the 229 households lived in Purfleet, reflecting the higher number of residents per household there.

Table 1: Aboriginal households and usual residents, by location

Location	Number of households	Aboriginal usual residents	Non-Aboriginal usual residents	Residents per household
Purfleet	46	242	4	5.3
Taree town	99	380	38	4.2
Cabarita	41	168	10	4.3
Forster-Tuncurry	16	46	12	3.6
Other	27	71	28	3.7
All locations	229	907	92	4.4

It is not possible to be certain, but it is believed that only about 20 households were not surveyed. For known households, the reasons for not being surveyed were:

- contact could not be made
- interviews could not be arranged within the time limits of the study
- interview was refused.

There were only two direct refusals, but three other households were regarded as indirect refusals to be interviewed. In terms of the likely total number of households, the overall response rate therefore was about 92 per cent.

Of the 907 Aboriginal people surveyed who were usually resident in the Taree area, 469 (51.7 per cent) were male and 438 (48.3 per cent) were female (Table 2). Almost 44 per cent of males and almost 42 per cent of females were aged 14 years or less, and only 1.9 per cent of males and 2.5 per cent of females were aged 65 years or more. The mean age of males was 21.0 years, and the median 17.0 years. The mean age of females was 22.5 years and the median 19.0 years.

Table 2: Aboriginal usual residents of the Taree area who were surveyed, by sex and age group

	Male	es	Fema	les	Perso	Persons	
Age group (years)	No.	%	No.	%	No.	%	
0–4	66	14.1	70	16.0	136	15.0	
5–9	76	16.2	65	14.8	141	15.5	
10–14	64	13.6	48	11.0	112	12.3	
15–19	58	12.4	38	8.7	96	10.6	
20–24	40	8.5	47	10.7	87	9.6	
25–29	33	7.0	29	6.6	62	6.8	
30–34	39	8.3	44	10.0	83	9.2	
35–39	30	6.4	24	5.5	54	6.0	
40–44	21	4.5	21	4.8	42	4.6	
45–49	8	1.7	9	2.1	17	1.9	
50–54	6	1.3	12	2.7	18	2.0	
55–59	10	2.1	12	2.7	22	2.4	
60–64	9	1.9	8	1.8	17	1.9	
65 and older	9	1.9	11	2.5	20	2.2	
All ages	469	100.00	438	100.00	907	100.00	

3.2 Number of people with disabilities and handicaps

Of the 907 Aboriginal usual residents of the Taree area included in the study, 227 (25.0 per cent) were identified as having one or more disabilities, 124 (13.7 per cent) were identified as being as being handicapped by their disability and 46 (5.1 per cent) were identified as being severely handicapped (Table 3).

Table 3: Disability and handicap status of Aboriginal usual residents of the Taree area, by location

	Number of	Disabled		Handicapped		Severely handicapped	
Location	residents	No.	%	No.	%	No.	%
Purfleet	242	53	21.9	28	11.6	9	3.7
Taree	380	106	27.9	63	16.6	24	6.3
Cabarita	168	31	18.5	16	9.5	7	4.2
Forster-Tuncurry	46	13	28.3	6	13.0	1	2.2
Other	71	24	33.8	11	15.5	5	7.0
All locations	907	227	25.0	124	13.7	46	5.1

Of the 227 people identified by the household questionnaire as having one or more disabilities, further information about the disabilities and any handicaps associated with the disability was obtained by way of an individual questionnaire for 221. Six people did not complete the individual questionnaire making it difficult to elaborate on the information obtained in the household questionnaire. For these six people, information collected in the household questionnaire was used to classify their disability, but no details were available about the existence and nature of any handicap associated with the disability, or of the use of aids or need for assistance.

Of the 221 individual questionnaires completed, 141 (64 per cent) were undertaken directly with the person identified by the household questionnaire as having one or more disabilities, and 80 (36 per cent) by means of a proxy. More than four-fifths of the individual questionnaires completed by a proxy were necessary because the person identified as having a disability was aged 15 years or less (Table 4). Five questionnaires were completed by proxy because the person identified as having a disability was unable to respond because of the condition, and nine because of temporary absence from the household or study area.

Table 4: Reasons for individual questionnaires being completed by proxy, by relationship to person with disability

	Reason							
Relationship to person with disability	Aged 15 years or less	Unable to respond because of condition	Unable to respond because of absence					
Mother	36	2	4					
Father	15	_	1					
Foster parent	2	1	-					
Guardian	2	_	-					
Grandparent	5	_	-					
Other	4	2	3					
Not specified	2	_	1					
All relationships	66	5	9					

Disabilities and handicaps by residence

As noted above, one-quarter of all people surveyed reported having one or more disabilities; more than one-eighth were handicapped by their disability and one-intwenty were severely handicapped (Table 3). Cabarita residents reported lower levels of disability and handicap than the other locations surveyed, and levels of handicap were highest for residents of Taree, Chatham and Cundletown. More than one-third of residents of the towns and communities grouped as 'Other' (see Methods) reported having one or more disabilities. This group also reported the highest proportion of severe handicap.

Disabilities and handicaps by sex and age

Of the 469 Aboriginal male usual residents of the Taree area, 117 (24.9 per cent) reported one or more disabilities, and 65 (13.9 per cent) reported being handicapped by their disability (Table 5). Of the 65 males with handicaps for whom severity of handicap was determined, 23 (4.9 per cent) reported being severely handicapped. The prevalence of disability for Aboriginal female usual residents was similar, with 110 (25.1 per cent) of the 438 females reporting one or more disabilities (Table 6). The prevalences of handicap (59 females reporting being handicapped; 13.9 per cent) and severe handicap (23 females; 5.3 per cent) for females were also similar to those for males.

Table 5: Disability and handicap status of Aboriginal male usual residents of the Taree area, by age group

Age group		Disabled		Handi	Handicapped		Severely handicapped	
(years)	Population	No.	%	No.	%	No.	%	
0–4	66	8	12.1	8	12.1	(a)	-	
5–9	76	20	26.3	10	13.2	7	9.2	
10–14	64	12	18.8	5	7.8	1	1.6	
15–19	58	12	20.7	8	13.8	3	5.2	
20–24	40	8	20.0	3	7.5	2	5.0	
25–29	33	3	9.1	1	3.0	0	0.0	
30–34	39	11	28.2	6	15.4	2	5.1	
35–39	30	10	33.3	3	10.0	3	10.0	
40–44	21	6	28.6	4	19.0	3	14.3	
45–49	8	4	50.0	4	50.0	1	12.5	
50-54	6	4	66.7	3	50.0	0	0.0	
55–59	10	9	90.0	6	60.0	0	0.0	
60–64	9	3	33.3	1	11.1	0	0.0	
65 and older	9	7	77.8	3	33.3	1	11.1	
All ages	469	117	24.9	65	13.9	23	4.9	

⁽a) Severity of handicap was not determined for the 0 to 4 year age group.

The prevalence of disability increased with age for Aboriginal usual residents of the Taree area, as it does for the total Australian population (Figures 1 and 2). At all ages, the prevalence for Aborigines exceeded that of the total population. For each population, the age-specific prevalences of disability were generally similar for males and females. Similarly, the prevalence of handicaps increases with age for both populations, with higher prevalences for Aborigines generally than for the total population.

Table 6: Disability and handicap status of Aboriginal female usual residents of the Taree area, by age group

Age group		Disabled		Handicapped		Severely handicapped	
(years)	Population	No.	%	No.	%	No.	%
0–4	70	6	8.6	6	8.6	(a)	-
5–9	65	16	24.6	10	15.4	6	9.2
10–14	48	4	8.3	3	6.3	2	4.2
15–19	38	8	21.1	3	7.9	1	2.6
20–24	47	10	21.3	6	12.8	3	6.4
25–29	29	4	13.8	1	3.4	0	0.0
30–34	44	12	27.3	2	4.5	0	0.0
35–39	24	8	33.3	5	20.8	2	8.3
40–44	21	7	33.3	1	4.8	0	0.0
45–49	9	6	66.7	5	55.6	3	33.3
50-54	12	9	75.0	5	41.7	2	16.7
55–59	12	5	41.7	2	16.7	0	0.0
60–64	8	6	75.0	5	62.5	1	12.5
65 and older	11	9	81.8	5	45.5	3	27.3
All ages	438	110	25.1	59	13.5	23	5.3

⁽a) Severity of handicap was not determined for the 0 to 4 year age group.

Standardised prevalence of disabilities and handicaps

As noted in Methods, comparison of overall levels of disability and handicap for the Aboriginal and total Australian populations requires adjustment for differences in the age structures of the two populations. Aboriginal males were 2.5 times more likely to have a disability than were non-Aboriginal Australian males and 1.7 times more likely to be handicapped (Table 7). Similar differences were seen between Aboriginal females and non-Aboriginal Australian females. Severe handicap was 2.4 times more common in Aboriginal males and 2.3 times more common in Aboriginal females than in the general population.

Table 7: Age-adjusted disability and handicap ratios, by $sex^{(a)}$

Sex	Disability	Handicap	Severe handicap
Male	2.5 (2.1–3.0)	1.7 (1.4–2.1)	2.4 (1.5–3.6)
Female	2.9 (2.4–3.5)	1.8 (1.5–2.3)	2.3 (1.5–3.4)

⁽a) Figures in parentheses are 95% confidence intervals.

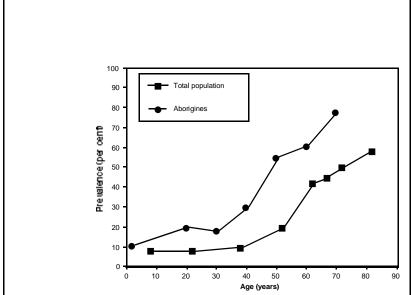


Figure 1: Prevalence of disabilities for Aboriginal male usual residents of the Taree area of New South Wales and the total Australian population, 1988-90

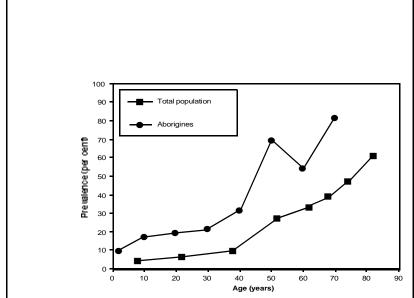


Figure 2: Prevalence of disabilities for Aboriginal female usual residents of the Taree area of New South Wales and the total Australian population, 1988–90

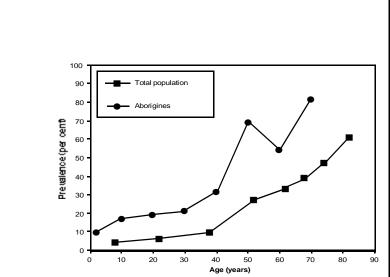
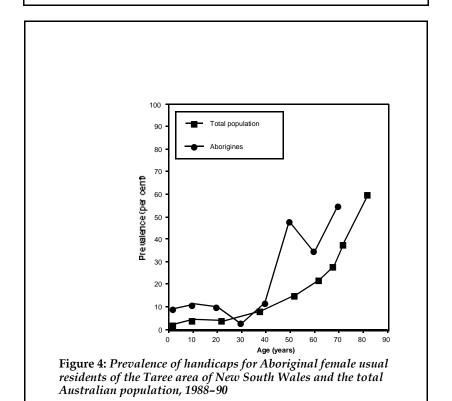


Figure 3: Prevalence of handicaps for Aboriginal male usual residents of the Taree area of New South Wales and the total Australian population, 1988-90



3.3 The disabilities

The 227 people who were identified as having one or more disabilities reported a total of 406 disabilities: 117 males reported a total of 202 disabilities and 110 females reported a total of 204 disabilities (Table 8).

The most frequently reported group of disabilities were those classified as disorders of the sense organs, for which there were 76 disabilities reported (19 per cent of all disabilities). This group included the most frequently reported specific disability—hearing loss—which was reported by 46 people (5.1 per cent of usual residents). Thirteen people (1.4 per cent) reported some loss of sight.

Disorders of the musculoskeletal system and connective tissues was the second most frequently reported group, with a total of 64 disabilities reported (16 per cent of all disabilities). The next most frequently reported groups were circulatory system disorders (60 disabilities reported; 15 per cent of all disabilities) and respiratory system disorders (52 disabilities; 13 per cent).

After hearing loss, the most frequently reported specific disabilities were:

- asthma reported by 45 people (5.0 per cent of usual residents)
- slow at learning and specific delays in development—reported by 37 people (4.1 per cent)
- heart disease reported by 36 people (4.0 per cent)
- unspecified mental, nervous or emotional conditions—reported by 26 people (2.9 per cent)
- diabetes mellitus reported by 20 people (2.2 per cent)
- arthritis and related disorders, other than of the back—reported by 19 people (2.1 per cent)
- hypertensive disease reported by 18 people (2.0 per cent)
- arthritis and related disorders of the back reported by 17 people (1.9 per cent)
- speech impediment reported by 16 people (1.8 per cent).

For males, the most frequent primary disabling condition was slow at learning and specific delays in development, which affected 19 males (16.2 per cent of males with one or more disabilities) (Table 9). The next most frequently reported primary disabling conditions for males were hearing loss (16 males; 13.7 per cent of males with one or more disabilities), asthma (16; 13.7 per cent), heart disease (7; 6.0 per cent) and arthritis and related conditions of the back (7; 6.0 per cent).

For females, asthma was both the most frequently reported primary disabling condition (17 females; 15.5 per cent of females with one or more disabilities), followed by hearing loss (15; 13.6 per cent), unspecified mental, nervous or emotional conditions (12; 10.9 per cent), slow at learning and specific delays in development (9; 8.2 per cent) and diabetes mellitus (9; 8.2 per cent).

Table 8: All disabling conditions and primary disabling conditions, by sex

	All disabling conditions			Primary	Primary disabling condition		
-	Males	Females	Persons	Males	Females	Persons	
Mental disorders other than retardation, degeneration or slow at learning	8	20	28	5	13	18	
Senile psychoses	0	1	1	0	1	1	
Other psychoses	1	0	1	1	0	1	
Unspecified mental, nervous or emotional condition	7	19	26	4	12	16	
Mental retardation, mental degeneration due to brain dam- age, slow at learning and spe- cific delays in development	28	15	43	23	11	34	
Mental retardation	2	2	4	2	2	4	
Mental degeneration due to brain damage	2	0	2	2	0	2	
Slow at learning and specific delays in development	24	13	37	19	9	28	
Disorders of the sense organs	36	40	76	21	24	45	
Eye disorders—sight loss	6	7	13	4	4	8	
Eye disorders—no sight loss	4	8	12	0	5	5	
Ear disorders—hearing loss	22	24	46	16	15	31	
Ear disorders—no hearing loss	4	1	5	1	0	1	
Nervous system disorders	21	12	33	9	3	12	
Paralysis	0	3	3	0	1	1	
Epilespy	8	2	10	4	2	6	
Migraine	0	2	2	0	0	0	
Speech impediment	11	5	16	4	0	4	
Other disorders	2	0	2	1	0	1	
Circulatory system disorders	26	34	60	10	15	25	
Hypertensive disease	7	11	18	2	7	9	
Heart disease	17	19	36	7	7	14	
Rheumatic	0	4	4	0	1	1	
Other disorders	2	0	2	1	0	1	

(continued)

 ${\bf Table~8~(continued):}~All~disabling~conditions~and~primary~disabling~condition,~by~sex$

	All disabling conditions			Primary disabling condition		
_	Males	Females	Persons	Males	Females	Persons
Respiratory system disorders	24	28	52	19	17	36
Asthma	19	26	45	16	17	33
Chronic airways disease (including bronchitis and emphysema)	3	0	3	2	0	2
Other respiratory disorders	2	2	4	1	0	1
Disorders of the musculoskeletal system and connective tissues	38	26	64	21	13	34
Arthritis and related disorders of the back	11	6	17	7	4	11
Arthritis and related disorders, other than of the back	8	11	19	5	6	11
Absence of limbs or parts of limbs	2	2	4	2	1	3
Musculoskeletal deformities (excluding absence of limbs or parts of limbs)	10	2	12	5	0	5
Other disorders	7	5	12	2	2	4
Other disorders and conditions	21	29	50	9	14	23
Neoplasms	1	0	1	1	0	1
Diabetes mellitus	7	13	20	5	9	14
Other endocrine disorders	0	2	2	0	0	0
Ulcer—stomach or duodenum	1	2	3	0	0	0
Other digestive disorders	2	0	21	1	0	1
Abdominal hernia	1	1	2	0	1	1
Skin and subcutaneous skin disorders	1	2	3	1	0	1
Alcohol dependence	4	1	5	1	0	1
Uriinary tract disorders	0	7	7	0	4	4
Other disorders	4	1	5	0	0	0
All conditions	202	204	406	117	110	227

Table 9: Most frequently reported disabling and primary disabling condition, (a) by sex

	Any repo	orted condition	Primary disabling condition		
Sex/condition ^(b)	Number	Prevalence (%) ^(c)	Number	Proportion (%) ^(c)	
Males					
slow at learning or developmental delays	24	5.1	19	16.2	
Hearing loss	22	4.7	16	13.7	
Asthma	19	4.1	16	13.7	
Heart disease	17	3.6	7	6.0	
Speech impediment	11	2.3	4	3.4	
Arthritis of the back	11	2.3	7	6.0	
Musculoskeletal deformities	10	2.1	5	4.3	
Epilepsy	8	1.7	4	3.4	
Females					
Asthma	26	5.9	17	15.5	
Hearing loss	24	5.5	15	13.6	
Unspecified—mental, nervous or emotional	19	4.3	12	10.9	
Heart disease	19	4.3	7	6.4	
slow at learning or developmental delays	13	3.0	9	8.2	
Diabetes mellitus	13	3.0	9	8.2	
Hypertensive disease	11	2.5	7	6.4	
Arthritis—other than back	11	2.5	6	5.5	

⁽a) See Methods for explanations of reported disabling and primary disabling conditions.

⁽b) See Table 8 for full wording of condition descriptions, which have been abbreviated in this table.

⁽c) Prevalence is the percentage of the total population of usual residents for each sex reporting the condition; proportion is the percentage of males or females identified as having one or more disabilities who reported the condition as the primary disabling condition. The crude prevalences reported here are not directly comparable with those for the total population because of the differences in the age structures of the Aboriginal and total populations.

3.4 The handicaps

More than one-eighth of Aboriginal usual residents of the Taree area reported being handicapped by their disabilities, and one-twentieth were severely handicapped (Table 3).

Overall, more handicapped people suffered from a mobility handicap than any other type of handicap (Table 10). Of the 130 people identified as being handicapped by their disability, 87 (66.9 per cent) reported a mobility handicap. The next frequently reported areas of handicaps were employment (80 people; 61.5 per cent of people with a handicap) and education (74; 56.9 per cent). For males, the most frequently reported area of handicap was employment (44 males; 67.7 per cent of males with a handicap), and for females it was mobility (44 females; 67.7 per cent).

Table 10: Area of handicap, (a) by sex

	Males			Females	Persons		
Area of handicap	No.	Prevalence (%) ^(b)	No.	Prevalence (%) ^(b)	No.	Prevalence (%) ^(b)	
Personal care	32	6.8	19	4.3	51	5.6	
Mobility	43	9.2	44	10.0	87	9.6	
Communication	11	2.3	8	1.8	19	2.1	
Education	39	8.3	35	8.0	74	8.2	
Employment	44	9.4	36	8.2	80	8.8	

⁽a) See Methods for explanations of areas of handicap.

For those males and females identified as being handicapped by their disability, disorders of the musculoskeletal system and connective tissues was the most frequently reported group of primary disabling conditions, followed by mental retardation, mental degeneration due to brain damage, slow at learning and specific delays in development (Table 11).

For those with severe handicaps, mobility was also the most frequently reported area of handicap, with 16 males (69.6 per cent of those with a severe handicap) and 18 females (78.3 per cent) being handicapped in that way (Table 12). For males, mental retardation, mental degeneration due to brain damage, slow at learning and specific delays in development was the most frequently reported group of primary disabling conditions associated with severe handicaps, and for females this group and disorders of the musculoskeletal system and connective tissues were equally common.

⁽b) Prevalence is the percentage of the total population of usual residents for each sex reporting the area of handicap. The crude prevalences reported here are not directly comparable with those for the total population because of the differences in the age structures of the Aboriginal and total populations.

Table 11: Area of handicap by sex and type of primary disabling condition^(a,b)

Sex/area of handicap	Mental other than retard- ation	Mental retard- ation etc.	Sense organ disorder	Nervous system disorder	tory system	system	Musculo/ skeletal disorder	Other disorder	All condi- tions
Males									
Personal care	2	8	5	1	2	4	8	2	32
Mobility	1	9	3	2	3	7	14	4	43
Commun- ication	1	4	2	1	1	1	0	1	11
Education	2	15	6	4	0	7	4	1	39
Employ- ment	3	7	4	3	3	4	16	4	44
Females									
Personal care	2	3	4	2	2	2	3	1	19
Mobility	4	4	5	2	9	7	8	5	44
Commun- ication	1	4	3	0	0	0	0	0	8
Education	3	9	7	1	2	7	6	0	35
Employ- ment	3	3	3	2	9	6	7	3	36

⁽a) See Methods for explanations of areas of handicap, and Table 8 for full wording of condition descriptions, which have been abbreviated in this table.

3.5 Use of aids and receipt of assistance

Sixteen males (24.6 per cent of those identified as handicapped) and 10 females (15.4 per cent) reported the use of some type of aid (Table 13). Most females reporting the use of an aid were severely handicapped, but fewer males with a severe handicap used an aid than did those with a moderate or mild handicap.

⁽b) The sums of the components are greater than the numbers of males and females with handicaps because some people are handicapped in more than one area.

Table 12: Severe handicaps—area of handicap by sex and type of primary disabling condition^(a,b)

Sex/area of handicap ^(c)	Mental other than retarda- tion	Mental retarda- tion etc.	Sense organ disorder	Nervous system disorder	Circul- atory system disorder	Res- piratory system disorder	Musculo/ skeletal disorder	Other disorder	All con- ditions
Males									
Personal care	2	4	1	0	0	4	O	1	12
Mobility	1	5	5 1	1	0	3	3	2	16
Commu- nication	1	3	0	0	0	0	0	1	5
Females									
Personal care	2	1	2	1	1	2	2	. 0	11
Mobility	3	3	0	2	2	2	5	1	18
Commu- nication	1	3	3 1	0	0	0	C	0	5

⁽a) See Methods for explanations of areas of handicap, and Table 8 for full wording of condition descriptions, which have been abbreviated in this table.

Table 13: People with handicaps using aids, (a) by sex and severity of handicap (a,b)

Severity of handicap	Males			Females	Persons		
	No.	Prevalence (%) ^(c)	No.	Prevalence (%) ^(c)	No.	Prevalence (%) ^(c)	
Severe	4	0.9	6	1.4	10	1.1	
Moderate	6	1.3	1	0.2	7	0.8	
Mild	6	1.3	3	0.7	9	1.0	
All severities(b)	16	3.4	10	2.3	26	2.9	

⁽a) See Methods for explanations of aids and severity of handicap.

⁽b) The sums of the components are greater than the numbers of males and females with severe handicaps because some people have a severe handicap in more than one area.

⁽c) Severity of handicap was not assessed for children aged less than 5 years or for education or employment handicaps.

⁽b) Does not include people with handicaps of undetermined severity; percentages may not add exactly due to rounding.

⁽c) Prevalence is the percentage of the total population of usual residents for each sex reporting the use of aids. The crude prevalences reported here are not directly comparable with those for the total population because of the differences in the age structures of the Aboriginal and total populations.

The areas of handicap for which aids were used also differed between males and females, with more males using an aid for personal care than for mobility or communication (Table 14). For females, the use of aids was evenly distributed through the three areas of handicap.

Table 14: People with handicaps using aids, by sex and area of handicap^(a,b)

Anna of		Males		Females		Persons		
Area of handicap	No.	Prevalence (%) ^(c)	No.	Prevalence (%) ^(c)	No.	Prevalence (%) ^(c)		
Personal care	10	2.1	5	1.1	15	1.7		
—Washing	5	1.1	5	1.1	10	1.1		
—Dressing	1	0.2	1	0.2	2	0.2		
—Eating	1	0.2	2	0.5	3	0.3		
—Toiletting	0	0.0	3	0.7	3	0.3		
—Other	3	0.6	1	0.2	4	0.4		
Mobility	5	1.1	5	1.1	10	1.1		
Communica- tion ^(d)	3	0.6	4	0.9	7	0.8		
Any area of handicap	16	3.4	10	2.3	26	2.9		

⁽a) See Methods for explanations of aids and areas of handicap.

Twenty-eight males (43.1 per cent of those identified as handicapped) and 20 females (30.8 per cent) reported receiving some assistance in dealing with their handicap (Table 15). The area of handicap for which males most frequently received assistance was personal care, and for females it was transport (Table 16).

Of people identified as being handicapped by their disability, four males (6.2 per cent of those identified as handicapped) and four females (6.2 per cent) reported having a need for more assistance (Table 17). All of these people reported needing more assistance in the area of personal care, and three-quarters reported a need for assistance in dealing with a communication handicap.

⁽b) Totals for broad areas of handicap may be less than the sums of the numbers for specific areas of handicap, since persons may use aids in more than one specific area of handicap.

⁽c) Prevalence is the percentage of the total population of usual residents for each sex reporting the use of aids. The crude prevalences reported here are not directly comparable with those for the total population because of the differences in the age structures of the Aboriginal and total populations.

⁽d) Includes hearing aids.

Table 15: People receiving assistance for handicaps, by sex and severity of handicap^(a,b)

Soverity of	Males			Females	Persons		
Severity of handicap	No.	Prevalence (%) ^(c)	No.	Prevalence (%) ^(c)	No.	Prevalence (%) ^(c)	
Severe	15	3.2	15	3.4	30	3.3	
Moderate	11	2.3	2	0.5	13	1.4	
Mild	2	0.4	3	0.7	5	0.6	
All severities(b)	28	6.0	20	4.6	48	5.3	

- (a) See Methods for explanations of aids and severity of handicap.
- (b) Does not include people with handicaps of undetermined severity.
- (c) Prevalence is the percentage of the total population of usual residents for each sex reporting the use of aids. The crude prevalences reported here are not directly comparable with those for the total population because of the differences in the age structures of the Aboriginal and total populations.

Table 16: People receiving assistance for handicaps, by sex and area of handicap $^{(a,b)}$

		Males		Females		Persons
Area of handicap	No.	Prevalence (%) ^(c)	No.	Prevalence (%) ^(c)	No.	Prevalence (%)(c)
Personal care	17	3.6	13	3.0	30	3.3
—Washing	4	0.9	6	1.4	10	1.1
—Dressing	9	1.9	6	1.4	15	1.7
—Eating	3	0.6	4	0.9	7	0.8
—Toiletting	2	0.4	4	0.9	6	0.7
—Bladder or bowel control	4	0.9	4	0.9	8	0.9
—Footcare	4	0.9	7	1.6	11	1.2
—Medicines or wound dressings	2	0.4	2	0.5	4	0.4
Mobility	12	2.6	12	2.7	24	2.6
—In the home	5	1.1	6	1.4	11	1.2
—In or out of bed or chair	3	0.6	4	0.9	7	0.8
—Away from home	4	0.9	3	0.7	7	0.8
Transport	13	2.8	16	3.7	29	3.2
Communication	3	0.6	0	0.0	3	0.3

⁽a) See Methods for explanations of areas of handicap.

⁽b) Totals for broad areas of activity may be less than the sums of the numbers for specific areas of activity, since persons may receive help in more than one specific area of activity.

⁽c) Prevalence is the percentage of the total population of usual residents for each sex reporting needing or receiving help. The crude prevalences reported here are not directly comparable with those for the total population because of the differences in the age structures of the Aboriginal and total populations.

Table 17: People with need for more assistance, by sex and area of handicap^(a)

Males			Females	Persons		
Area of handicap	No.	Prevalence (%) ^(b)	No.	Prevalence (%) ^(b)	No.	Prevalence (%) ^(b)
Personal care	4	0.9	4	0.9	8	0.9
Mobility	2	0.4	2	0.5	4	0.4
Transport	3	0.6	1	0.2	4	0.4
Communication	3	0.6	3	0.7	6	0.7

⁽a) See Methods for explanations of areas of handicap.

⁽b) Prevalence is the percentage of the total population of usual residents for each sex reporting needing or receiving help. The crude prevalences reported here are not directly comparable with those for the total population because of the differences in the age structures of the Aboriginal and total populations.

4 Discussion

The levels of disability, handicap and severe handicap of Aborigines living in the Taree area of New South Wales are much higher than those reported by the Australian Bureau of Statistics for the total Australian population (ABS 1990), but methodological differences between this study and the ABS survey raise a number of issues about the comparability of the results.

As noted in Study design, this study was limited to people living in households, whereas the ABS survey also included people living in health establishments and institutions for whom prevalences of disability and handicap were much higher than for people living in households (ABS 1990). The number of people living in health establishments and institutions was small, however, so this methodological difference results in only a slight underestimate of the age-adjusted disability and handicap ratios between Aborigines and the total population.

The other major methodological difference concerns selection of the study population. The ABS survey sample was selected from the total Australian population using multistage sampling, while this study attempted a census of the Aboriginal population living in the Taree area of New South Wales. This difference raises two questions: how successful was the attempted census and how representative of the Australian Aboriginal population is the Aboriginal population living in the Taree area?

It is believed that only about 20 Aboriginal households in the Taree area were not included in the study. If this estimate is correct, and there is no way of being certain, the overall response rate for households was around 92 per cent. Assuming that these households had the same number of residents per household as other Aboriginal people living in the area, but the same prevalences of disabilities and disabilities as the total Australian population, the prevalences for the estimated total Aboriginal population of the area would be marginally lower than those for people included in the study—24.2 per cent compared with 25.0 per cent for disabilities, 13.6 per cent compared with 13.7 per cent for handicaps and 5.0 per cent compared with 5.1 per cent for severe handicaps.

The Aboriginal population of Australia is very heterogeneous, and while the Aboriginal population living in the Taree area may be similar to other populations living in the southeast and southwest parts of the country, there are considerable differences between these populations and those living in more remote parts of the country. Consequently, it is likely that other Aboriginal populations in the southeast and southwest of Australia have similar levels of disability and handicap to those reported here, but it is impossible to predict levels for Aboriginal populations living in more remote parts of the country.

Comparison of estimates of prevalences of disability and handicap for different populations may be affected by differences in the comprehension of, and responses to, the questions asked, and by the extent to which the specific conditions are viewed by

particular populations as limiting or as normal (d'Espaignet and van Ommeren 1992; Schofield 1990). Pilot testing and feedback from the local Aboriginal interviewers suggested that the questions were well understood, but no formal attempt was made to assess the impact of any difference between Aborigines living in the Taree area and the total Australian population in comprehension of and responses to the questions asked. Similarly, the perception of specific conditions as being disabling or handicapping may vary between Aborigines living in the Taree area and the total Australian population. The level at which this occurs is not known but it is likely that the differences in perception would be greater for Aboriginal populations living in remote parts of Australia than for those living in the southeast and southwest of the country.

Studies about health conditions (including this one and the ABS survey) which rely on interviews without clinical evaluation raise important questions about the extent to which self-reported information adequately measures the frequency of specific conditions. A very early study of prevalences assessed by interview and clinical evaluation has reported dramatic differences, particularly for chronic conditions such as heart disease, hypertension, diabetes mellitus, ulcers, arthritis and hernias (Sanders 1962).

Certainly the crude prevalence of diabetes mellitus reported by respondents to this study (2.2 per cent) is much lower than the standardised prevalence of 7.8 per cent documented in a clinical assessment of Aboriginal residents of the Taree area in the mid-1980s (Williams et al. 1987). Similarly, the crude prevalence of diabetes mellitus reported by the Australian Bureau of Statistics' 1989–90 National Health Survey (1.1 per cent) is much lower than the generally quoted level of 3.4 per cent estimated from clinical assessment (Glatthaar et al. 1985). It was beyond the scope of this study to assess the differences between self-reported and clinically measured health information but, from the data on diabetes mellitus, it appears that the differences for Aborigines living in the Taree area are likely to be similar to those for the total Australian population.

Despite the methodological differences discussed, the prevalences of disability and handicap reported here for Aborigines living in the Taree area of New South Wales can be compared validly with those reported by the ABS for the total Australian population. As reflected in the age-adjusted disability and handicap ratios (between 1.7 and 2.9), the prevalences of disabilities and handicaps are much higher for these Aboriginal people than for the total Australian population. These much higher prevalences highlight the need for much more attention to be directed to health, disability and rehabilitation services for Aboriginal people.

The study provides essential information about specific disabilities and handicaps requiring attention. As suspected from other studies, hearing loss is a major problem for many Aboriginal people, and was identified as one of the main conditions responsible for a handicap in the area of education. Asthma, the second most frequently reported disabling condition, also made a substantial contribution to education and other handicaps. Aboriginal people reported high levels of slow learning and specific delays in development, particularly for males, for whom it was the most frequently identified primary disabling condition. Slow at learning and specific delays in development was the leading condition responsible for a handicap in the area of education for both males and females.

The levels of handicap reported by Aboriginal people living in the Taree area of New South Wales were much higher than those for the total Australian population, and the relative importance of the areas of handicap were somewhat different. Overall, a mobility handicap was the most frequently reported area of handicap for Aborigines and the total population. However, higher proportions of Aboriginal people with a handicap reported being handicapped in the areas of employment and particularly education than did people in the total population.

Some of the findings of this study provide the basis for immediate action, while others may require further investigation. There is certainly a need to assess the levels of disability and handicap for Aboriginal people in other parts of Australia, given the very high levels reported in this study. Such an assessment could involve an Australia-wide sample survey along the lines of the ABS survey. A better alternative might be the replication of attempted censuses, such as this study, in a sample of Aboriginal communities (including a variety of community types). A series of such censuses would be much more manageable than an Australia-wide survey. This approach also has the very distinct advantages of being undertaken in partnership with Aboriginal communities (rather than being largely imposed from outside) and of being able to contribute directly to the health planning for these communities. Certainly the experience of this study undertaken in partnership with the Biripi Aboriginal Corporation Medical Service was very successful and suggests that such partnerships should work well throughout Australia.

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Appendix

Disability and handicap—definition of terms²

Based broadly on World Health Organization recommendations (WHO 1980), the ABS defines a disabled person as someone who has one or more disabilities or impairments which have lasted or are likely to last six months or more, and a handicapped person as someone whose disability limits their capacity to perform tasks in one or more functional areas (ABS 1990).

Disabilities include both mental disorders and physical conditions. This study follows ABS's broad groupings of mental disorders and physical conditions, but has included a number of specific conditions of particular relevance for Aboriginal communities (for example, rheumatic heart disease).

Mental disorders

Mental disorders other than retardation, degeneration or slow at learning

- Senile psychoses
- · Other psychoses
- Unspecified mental, nervous or emotional condition

Mental retardation, mental degeneration due to brain damage, slow at learning and specific delays in development

- Mental retardation
- Mental degeneration due to brain damage
- Slow at learning and specific delays in development

Physical conditions

Disorders of the sense organs

- Eye disorders sight loss
- Eye disorders no sight loss
- Ear disorders hearing loss
- Ear disorders—no hearing loss

^{2.} The details presented here have been adapted from those presented by the Australian Bureau of Statistics in its report of the 1988 Survey of Aged and Disabled People (ABS 1990).

Nervous system disorders

- Paralysis
- Epilepsy
- Migraine
- Speech impediment
- Other disorders

Circulatory system disorders

- Hypertensive disease
- · Heart disease
- · Rheumatic heart disease
- Other disorders

Respiratory system disorders

- Asthma
- Chronic airways disease (including bronchitis and emphysema)
- Other respiratory disorders

Disorders of the musculoskeletal system and connective tissues

- Arthritis and related disorders of the back
- Arthritis and related disorders, other than of the back
- Absence of limbs or parts of limbs
- Musculoskeletal deformities (excluding absence of limbs or parts of limbs)
- Other disorders

Other disorders and conditions

- Neoplasms
- Diabetes mellitus
- Other endocrine disorders
- Ulcer stomach or duodenum
- Other digestive disorders
- Abdominal hernia
- Skin and subcutaneous tissue disorders
- Alcohol dependence
- Urinary tract disorders
- Other disorders

The primary disabling condition was defined as the condition identified by a person with more than one disability as causing the most problems. For a person with only one disabling condition, that condition was his or her primary disabling condition.

Handicap: for people with one or more disabilities, assessment was made of the degree to which their disability handicapped them in the performance of tasks in five functional areas:

- personal care difficulties in showering, bathing, using the toilet, dressing or eating;
- mobility difficulties moving around the home, moving around outside the home, walking 200 metres, walking up and down stairs or using public transport;
- verbal communication—difficulties understanding or being understood by strangers, family or friends in the person's native language;
- education—person unable to attend school, attended a special school, attended special classes in an ordinary school, needed time off from school or had difficulty at school because of disabling conditions;
- employment person permanently unable to work, restricted in type of work they
 could do, often needed time off work, restricted in number of hours they could work,
 would require an employer to make special arrangements or limited in prospects of
 obtaining, keeping or changing jobs (information collected for people aged 21 to 64
 years and those aged 15 to 20 years not attending school).

For people aged 5 years and older with a handicap, severity of handicap was assessed in the areas of personal care, mobility and verbal communication (severity of handicap was not assessed for people with only an education or employment handicap). The assessment was based on the person's ability to perform tasks in personal care, mobility and verbal communication and on the amount and type of assistance required. The severity of handicap for each person was defined as the highest level of severity in any of the three areas. Severity of handicap was classified as:

- severe—personal assistance or supervision required or the person was unable to perform one or more of the tasks;
- moderate—no personal assistance or supervision required, but the person had difficulty in performing one or more of the tasks;
- mild—no personal assistance or supervision required and the person had no difficulty in performing any of the tasks, but used an aid or had difficulty walking 200 metres or up and down stairs.

A person with one or more disabilities was assessed as needing assistance if they needed assistance or supervision to do one or more specified tasks or, in some cases, would find the tasks difficult to do alone. Assistance does not include the use of aids or appliances.

The person was assessed as needing assistance whether or not it was actually received. For those people receiving assistance, the source of the assistance could be individuals or organisations, and it could be formal or informal.

An aid was defined as a device or appliance used by a person with a disability to help them perform tasks. Aids include such devices as dressing hooks, special cutlery for eating, appliances to assist with washing and toiletting (including rails and straps), artificial limbs, wheelchairs, walking sticks, and hearing, speaking and writing aids. In this study, help of a personal or organisational nature was not considered an aid.