

7 Summary and conclusion

The analyses in the previous chapters of this report reveal the complexity and variability of the relationships among aspects of disability, related health conditions and other factors, both personal and environmental.

This chapter discusses and contrasts some of these interrelationships, and goes on to outline the reasons for caution in disability-related analyses, the need to ensure that analytical purposes and methods are well aligned, and the desirability of holistic analytical approaches to disability data.

7.1 Estimating the prevalence of health conditions related to disability

Chapter 3 compared prevalence estimates of health conditions from three sources: the Australian National Health Survey, the Australian Survey of Disability, Ageing and Carers and the Australian burden of disease study. Differences among the estimates were found, relating to survey design and screening (sample catchment) method, as well as the different focus and method of the three sources.

The comparison of prevalence from the health and disability surveys revealed (Table 3.2):

- The prevalence rates from the health survey were generally higher than those from the disability survey – which is to be expected, since the disability survey recorded conditions that were more likely to be associated with impairments or activity limitations.
- This pattern was not universal, with heart and stroke conditions estimated to be more prevalent from the disability survey (possibly because of the screening questions and the exclusion of people in cared accommodation from the health survey).
- Nevertheless, the ‘top 10’ conditions in the two surveys had nine conditions in common: arthritis, back problems, hypertension, total hearing, asthma, heart disease, diabetes, ‘total vision’, depression; the non-matching 10th conditions were stroke, which was in the top 10 conditions in the disability survey, and migraine in the health survey.

The burden of disease study used a range of data sources and yielded prevalence estimates different again, often lower than the health survey estimates but higher than the disability survey estimates (Table 3.3).

Thus we see that prevalence of health conditions is a measure sensitive to method.

7.2 Disability and related health conditions

In chapters 4 and 5 we looked at the relationships between disability and health conditions in several ways. Two contrasting analyses, focused on two of the main questions raised in Chapter 1, illustrate some of the differing findings.

Among people with severe disabilities, what were the most common associated diseases or health conditions?

When severe disability (severe or profound core activity restriction in the ABS disability survey) in the population was examined, which were the most common associated diseases or conditions in 1998?

The most common condition associated with 'severe disability' was arthritis, with 2.0% of people of all ages having severe disability and arthritis (Section 3.3: Table 3.4).

Other conditions that came to the fore on this criterion are:

- hearing conditions and back problems, with 1.6% of people having severe disability and these conditions
- hypertension, speech problems, heart disease and vision problems (1.1%, 1.0%, 0.9% and 0.9% respectively, of people having severe disability and these conditions).

It is worth noting that this report does not say that these diseases account for relatively high proportions of disability, because the ICF model carefully does not suggest simple causative relationships. Rather it acknowledges that a health condition is one of several important factors in the creation of disability.

Which health conditions were the most likely to be associated with severe disability?

When health conditions, and how likely each one is to be associated with severe disability were considered, a different picture emerged.

The conditions most likely to be associated with 'severe disability' in 1998 were (Section 5.3, Table 5.2):

- Autism – 95.3% of people with these conditions reported severe disability
- Dementia – 93.6% of people with these conditions reported severe disability
- Down syndrome – 91.5% of people reported severe disability
- Cerebral palsy – 83.6% of people reported severe disability
- More than 50% of people with the following conditions reported 'severe disability' – Parkinson's disease (75.4%), multiple sclerosis (73.3%), paralysis (58.6%), cataract (51.9%) and schizophrenia (50.2%).

It is important to remember here that the data come from a population survey and these percentages could be affected by people's ability or willingness to name the health condition. It may be, for instance, that it is only at a certain severity level that diagnosis of dementia happens and is able to be reported by the person or carer. That is, the disability may be severe before the condition is given a name, effectively leading to under-reporting and contributing to the high percentage reporting severe disability.

More detailed findings were:

- The overall pattern depicts a quite different picture compared to that based on the estimated frequencies of specific health conditions. Many conditions that were on the top

of the list in terms of their frequencies (Table 3.4) were ranked towards the bottom of the list in terms of the likelihood of being associated with a severe or profound core activity restriction (Table 5.2 and Figure 5.2). These include asthma (12% of people with this condition had a severe or profound core activity restriction), hypertension (15%), back problems (19%), arthritis (23%) and hearing (23%).

- For people aged under 65, conditions associated with congenitally related disorders or occurring in early childhood were ranked highest: autism (95% of people with this condition had a severe or profound core activity restriction), Down syndrome (92%) and cerebral palsy (83%).
- Dementia led the list for people aged 65 or over (96% of people with this condition had a severe or profound core activity restriction), followed by schizophrenia (93%), speech problems (90%) and Parkinson's disease (82%). Most of these conditions are highly related to age.¹⁹
- It should be noted that the estimates were based on all reported conditions. The associations between health conditions and activity limitations are complex. An activity limitation may be associated with a number of different health conditions, or with just one of a number of reported conditions, and it is not generally possible to tell which from the survey data. Multiple conditions are more common among older people. Two persons with the same health condition can have different levels of activity limitation, and two persons with the same level of activity limitation do not necessarily have the same health condition. Environmental factors play a role in the creation of disability, and this would account for further variability in the relationship between health conditions and disability.

Prevalence of a health condition did not indicate prevalence or severity of associated disability

The bivariate analyses of chapters 4 and 5 found that, when health conditions were examined in terms of their associations with prevalence and severity of disability using the two groups of severity measures, there was a wide range of possibilities (sections 3.3, 4.2, 5.3, 5.4 and 5.5):

- high disability prevalence but low level of severity (e.g. arthritis, back problems, hearing, hypertension and asthma)
- low disability prevalence but high level of severity (e.g. autism, dementia, Down syndrome, cerebral palsy and Parkinson's disease)
- high disability prevalence and high level of severity (e.g. speech problems which were more likely to be associated with intellectual and learning conditions for children, and stroke and dementia for older people)
- high dependence on health service system but low dependence on community system (e.g. hypertension, arthritis, heart disease, asthma and diabetes)
- high dependence on community system but lower dependence on health system (e.g. autism)
- high dependence on both health and community systems (e.g. dementia and stroke)

¹⁹ The estimates for ADHD, Down syndrome and cerebral palsy in this age group have very high relative standard errors and are considered too unreliable for this comparison.

- some conditions were more likely to be associated with multiple diseases and impairments (e.g. dementia and stroke; Section 4.4)
- some conditions were more likely to be associated with needs for assistance in core activity while less likely to be related to multiple conditions (e.g. autism; Sections 4.3, 4.4, 5.3, 5.4 and 5.5)
- some conditions were more likely to be associated with severe employment restrictions among the working age population but less likely to be associated with need for assistance with core activities (e.g. diabetes, depression and arthritis; Section 5.6).

Multiple conditions

People with disability, particularly in older age groups, were very likely to report multiple conditions.

Analysis based on all disabling conditions

- Multiple conditions were reported among people with most of the selected conditions (Figure 4.5). People with dementia led the list, with an average of 4.7 conditions. The next in line was stroke (4.6), followed by glaucoma (4.5), osteoporosis (4.4), heart disease (4.4), cataracts (4.3), diabetes (4.2), depression (4.1) and hypertension (4.1).
- People less likely to report multiple conditions were those with ADHD (1.8), autism (2.1) and multiple sclerosis (2.2).
- It is worth noting that most people with ADHD and autism were children of school age and they were less likely to have conditions more commonly associated with older ages. This could contribute to the relatively low average number of conditions for people in these groups.

Patterns of associated conditions

People with dementia were likely to have other selected conditions, and six conditions were reported by over one-fifth of them: total hearing (43%), arthritis (32%), speech (30%), total vision (26%), heart diseases (26%) and stroke (23%) (Table 4.8). The proportion of people with depression (9.5%) was highest among people with dementia compared to people with other conditions.

People who had had strokes were the most likely to report heart diseases (31%) and diabetes (16%) as other conditions. People with stroke also reported high proportions with arthritis (42%), hypertension (37%) and total hearing (37%). For example, this relationship may be reflected in the pattern:

- Diabetes was most commonly reported by those with stroke (16%), hypertension (15%), heart disease (13%) and dementia (13%).
- Hypertension most frequently occurred among people with diabetes (38%), stroke (37%), osteoporosis (33%) and heart disease (32%).
- People with osteoporosis were the most likely to also report the highest proportion of arthritis (48%).

Of those conditions that more frequently occurred among younger people (Table A6.1), speech problems were reported by 76% of people with autism and 55% of people with

cerebral palsy. Asthma was reported by 23% of people with ADHD and 20% of people with autism.

The proportion reporting back problems (35%) was highest for people with depression, possibly because these conditions were more prevalent among older working-age people.

Patterns of associated disabilities

- People with dementia (by definition in the psychiatric disability group) were most likely to have multiple disabilities, 90% of them had physical/diverse disability, 80% intellectual disability, 69% sensory/speech disability and 16% disability associated with acquired brain injury (Figure 4.9; Table 4.9).
- High proportions of people with multiple associated disabilities were also found for people with autism, Down syndrome, cerebral palsy, Parkinson's disease, schizophrenia, speech and stroke, each with a relatively high proportion in three or more associated disability groups.

7.3 Alternative measures of severity

The outline of key results above (Section 7.2) has focused on the severity measure: 'severe or profound core activity restriction', that is, where assistance is needed with self-care, mobility and/or communication. Fairly similar results were found for the two alternative severity measures used in the bivariate analyses, as follows.

Number of core activities in which help is needed, for selected health conditions

- The overall pattern was similar to that for the proportion having a severe or profound core activity restriction (Section 5.3). People with dementia, Down syndrome and autism were more likely to have more needs for assistance; about 60% of people with those conditions needed help with all three core activities (Figure 5.3). A high proportion needing help with three activities was also reported by people with cerebral palsy (52%), speech problems (38%) and Parkinson's disease (35%).
- About 95% of people with autism (11,700), 84% of people with dementia (84,300), 83% of people with Down syndrome (8,300), and 78% of those with cerebral palsy (17,300) needed help with at least two core activities.
- Of people with paralysis, about 60% needed help with at least two core activities, including 26% who needed help with all three activities.
- In contrast, people with back problems, asthma, migraine, hypertension, arthritis and hearing disorders were ranked at the bottom of the list. Between 85% and 95% of people with these conditions either required no assistance or needed help with only one core activity.

Frequency of need for help with core activities, for selected health conditions

- Overall, the pattern is similar to those of the previous two measures. Dementia led the list with 75% of people with this condition needing help at least three times a day (Figure 5.4). About 60% of people with autism and 58% with cerebral palsy also needed

assistance three or more times a day, followed by Parkinson's disease (52%), speech problems (51%) and Down syndrome (48%).

- In contrast, conditions that were more likely to be associated with relatively low frequencies of need for help were back problems, migraine, hypertension, asthma, arthritis and hearing disorders. Only about 2–10% of people with those conditions required assistance six or more times a day.

7.4 Disability, health conditions and other factors: multivariate analyses

The multivariate analyses were designed to focus on the third main question asked in Chapter 1: What are the relationships between disability, environmental factors and personal factors as well as health conditions? How do these vary with different measures of 'severity' of disability?

The multivariate analyses of Chapter 6 did not reveal key indicators of disability severity from among all the factors it was possible to consider – health conditions, personal factors and environmental factors. Rather, they confirmed the complexity of relationships among disability severity, health conditions and personal and environmental factors.

Personal and environmental factors were found to be strongly related to severity of disability. The further variability in these relationships, according to specific health conditions, suggests that health conditions also play a complex and varying role in the creation of disability, although these effects are not simple to predict. The fact that a number of health conditions are very age-related (e.g. dementia and autism) further complicates the relationships. Overall, it appears likely that there are three-way interactions between the severity of disability, the environmental factors that may affect it, and the underlying long-term conditions associated with the disability.

The main results were reasonably similar for the severity measures examined: regularity of need for assistance with core activities (sometimes, always, never); frequency of need for assistance (daily, 3 times a day etc.); and hours of informal care. This may not be surprising given the probable relationship between these measures. The robustness of the results for most factors for the three measures suggests that the associations found do reflect relationships within the population.

The number of long-term conditions a person had was obviously highly correlated with the severity of disability, however measured. This means that co-morbidity is very important in examining the relationships between particular conditions and the severity of disability.

7.5 Contrasting disability-focused and health-focused analyses

What does this analysis contribute to the understanding of the ICF model of functioning and disability, and the relationships among its entities (Figure 1.1)? What does it contribute to disability measurement?

Sometimes it is easiest to draw out features of analysis when they are described as a contrast or comparison to alternative approaches. This section draws out some contrasts between the

exploratory analysis of this report and the 'burden of disease' studies (e.g. AIHW: Mathers et al. 1999).

Disease focused analyses

Disease focused analyses, such as the burden of disease studies, can be represented as follows:

Their purpose is to consider the 'consequences' and costs of specific diseases. This approach has applications in prioritising actions and interventions aimed at preventing disease and disease 'burden', as defined.

They start with a particular disease, estimate the prevalence in the population of relevance, describe a broad distribution of sequelae and apply weightings to these (e.g. obtained by person trade-off methods) in order to estimate or summarise the total 'burden' for people with that disease. 'Burden' may be short or long term.

The analysis allowed by this approach results in the assignment of metrics (years lost, costs, 'burden') to specific disease outcomes (as well as to some risk factors). This allows for the years lost due to 'disability' as defined to be combined with years lost due to mortality, and for diseases to be ranked in terms of their 'burden'. Co-morbidities are allowed for but, because the approach is disease-centred rather than person-centred, such co-morbidity adjustments are difficult.

The metrics used by such analyses include 'years lost' or 'healthy years lost' because of the disease. These metrics are combined or summed to construct corresponding summary measures across a number of diseases (or the whole set, constructed to be mutually exclusive). Problems in ascribing meaning to such summary measures arise from the perceived problems with the disability weightings (discussed extensively in the literature – see also Chapter 3) and the difficulty (so far) in allowing for co-morbidities.

This approach does not explore the creation of disability by the interplay among and within the various factors in the ICF model. In a disease-focused analysis this can also mean problems in understanding and allowing for co-morbidities.

Disability-focused analyses

The approach in this study is primarily a disability-focused analysis and can be represented as follows:

The purpose was to start by looking at disability and considering the correlates or factors influencing the disability experience. This approach has applications in programs that deal with managing the day-to-day reality of disability, or programs that require some understanding of the profiles of people with disability, and the associated factors influencing disability, perhaps so as to minimise the disabling effects of health conditions or environmental policies.

First, the total population with certain activity limitations was considered, and from there, data about related health conditions, demographic characteristics, and environmental factors were considered. The use of the ABS Survey of Disability, Ageing and Carers means that the focus was on disability lasting six months or more.

The analysis allowed by this approach included the description of disease or co-morbidities related to disability.

The metrics used in our study are population prevalence and disability 'severity'.

This approach does not consider disease where no disability was involved. It readily allowed the construction of summary measures of disability, as that was where the analysis started. (This is the case because the Australian disability survey was constructed to align well with the ICF; it defined core activities and made simple rules about combining activity limitation information.)

The contrast in ICF terms

One way of representing this contrast is by referring to the ICF model (see Figure 1.1).

Disability-focused analysis

In the disability focused analysis, activity limitations have been explored in their own right and 'disability' measures constructed using this one ICF component. In this study, simple bivariate analyses explored the relationships between various diseases and disability, while the more complex multivariate analyses explored the strength of the other inter-relationships in the ICF model, and sought the strongest relationships among the elements on which there are data, using the various available measures of disability.

Both sets of analyses confirmed the complexity of the disability phenomenon and of its relationship with health conditions. Prevalence of a health condition did not directly indicate prevalence or severity of associated disability; particular health conditions had higher probabilities of disability or severe disability. The multivariate analysis did not reveal key indicators of disability severity from among all the factors considered – health conditions, personal factors and environmental factors.

Disease-focused analyses

In the disease-focused analysis, the starting point was the health condition. The 'burden' of the health condition implicitly summarised (perhaps some of) the other components of the ICF model (e.g. activity limitations, participation restrictions, environmental factors such as aids and equipment or carers). This process of synthesis and summary happened during the assigning of weights (that is, in the heads of the experts and other people asked to assign values, or preferences, to different functional states described to them). This has some risks, as the ICF model illustrated the large number of inter-relationships among the relevant factors, and the analyses carried out in this report did not indicate obvious simplifications.

Purpose and method

This discussion illustrates that purpose and analytical method are interwoven, and that it is important to suit method to purpose as far as possible. Disease-focused analyses of 'disability' and 'disease burden', as described here, may be useful for disease costing and priority setting for disease prevention. There may be problems in ascribing a 'disability' meaning to the summary measures derived in these analyses.

Disability-focused analyses may be more relevant for understanding disability in the population, for designing services and environmental modifications, and for understanding

the inter-relationships in the ICF model – that is, the creation of disability and the relevant environmental and other factors affecting it.

7.6 Environmental factors

The absence of good data on the full range of environmental factors in the ICF will hamper disability data analysis for some years to come. The importance of environmental factors – recognised in the ICF – has been vividly illustrated in a comparative study on burden of disease measurement in developed and developing countries (Australia and Cameroon; Reidpath et al. 2001). The data analysis of the study was based on two groups of people (40 participants for each group) with paraplegia and epilepsy, respectively. The study found that paraplegia was rated as a ‘worse burden’ in Cameroon largely because of the physical environmental factors, while epilepsy was rated as a ‘worse burden’ in Australia largely because of the less tolerant social environment, in particular the attitudes to some visible behaviours. This study was designed as an empirical study which set out to examine the ‘evidence’ for the disability weights in burden of disease studies (Reidpath et al. 2001). To date, most critical reviews of the burden of disease measure and, in particular, its key technical basis – ‘disability weights’ – have tended to be theoretical in nature, and there have been few empirical studies. Given that the burden of disease estimate is mainly a population-based summary statistic measure, it is also useful to examine empirical evidence from population surveys.

7.7 Conclusion

Overall, the study has yielded rich detail about the relationships among disability, health conditions and other factors. It was found that:

- Prevalence of a health condition did not indicate prevalence or severity of associated disability.
- Ranking health conditions in terms of their prevalence gave very different results from ranking them in terms of the likelihood of their being associated with severe disability. Conditions such as asthma, hypertension, arthritis and hearing are relatively prevalent but relatively unlikely (less than 25%) to be associated with severe disability. In contrast, conditions associated with intellectual, learning, psychiatric and neurological disorders were less prevalent but very likely to be associated with severe disability. For instance, over 90% of people reporting autism, dementia or Down syndrome had severe disability.
- Looking yet another way at the relationship between disability and health conditions, it was found that the most common condition associated with ‘severe disability’ was arthritis, with 2.0% of people of all ages having severe disability and arthritis.
- The multivariate analyses conducted did not reveal key indicators of disability severity from among all the factors it was possible to consider – health conditions, personal factors and environmental factors. This confirms the ICF model of disability, as reflecting a complex interaction among a wide range of personal, health and environmental factors.

The brief discussion in this chapter, contrasting two approaches to the analysis of disability, suggests the need for care in aligning purpose and method, and in the application of results. Perhaps more desirably the development of more common or holistic approaches to the analysis of health and disability would minimise the risk of inappropriate application of

results. The complexity of human functioning and disability is not something that statistical and policy analysts can escape from.

With 'whole of government' approaches increasingly demanding that services focus on the person as a whole, and not subdivide areas of life to align with service 'silos', the analysis of disability and long-term conditions requires a more holistic analytical approach. Health and community care services will increasingly deal with chronic and long term conditions, and support people long term in the community. As people move between these services over longer periods of time, the 'whole person' and contextual model of the ICF provides a useful conceptual and information framework.

Overall, it is concluded that:

- understanding analytical methods and what policy purposes they suit (or do not suit) is a major responsibility of disability data analysts
- it may be time to work towards more common or holistic approaches to the analysis of health and disability to minimise the risk of inappropriate application of results
- 'whole of government' policies require a 'whole person' analysis of health and disability, and this provides further motivation to seek less fragmented analysis.