



Incontinence in Australia: prevalence, experience and cost

2009

Summary

Incontinence affects many people in Australia

An estimated 316,500 people experienced severe incontinence as it is defined in the 2009 *Survey of Disability, Ageing and Carers* (ABS 2009a; ABS 2009b). The corresponding number in 2003 was 284,500, but given the sample sizes in the source data, there is not a significant difference between these two reference years. The majority of people with severe incontinence in 2009 were female (209,000 or 66%).

In 2009, the number of people who always needed help or supervision with their bladder or bowel control was 144,400. About 96,100 people with disability aged 10 and over living in households (2.7% of the total) and 99,700 people living in cared accommodation (63.2%) used continence aids, irrespective of their level of incontinence.

Incontinence affects an individual's ability to participate in everyday activities

Needing assistance with bladder or bowel control will affect an individual's life in more ways than one. The labour force participation rate for people aged 15–64 who always or sometimes needed assistance with bladder or bowel control was 20.4%. This was substantially lower than those who had difficulty with bladder or bowel control but needed no assistance (42.3%) and those who had no difficulty at all (56.8%). Of people aged 15 and over, living in households, with severe incontinence, 87,100 reported they could not go out as often as they would like, compared with 74,400 who reported they could go out as often as they would like—this difference was not statistically significant.

Primary carers who manage incontinence have lower wellbeing

In 2009, 72,900 people identified themselves as a primary carer who helped manage another person's incontinence. The majority of these primary carers (73.0%) reported spending 40 hours or more each week actively caring or supervising. Also, more primary carers who usually assisted with managing bladder or bowel control reported a change in their physical or emotional wellbeing (49.6%), weariness and lacking energy (45.0%) or worry or depression

(39.5%) due to their caring role, compared with carers who did not assist with managing another person's incontinence (30.4%, 30.2% and 28.7% respectively). The higher care needs of people with incontinence and the greater effect on primary carers may be directly due to incontinence, or the differing types and severity of disability of people who have incontinence, or a combination of both.

The health care costs of incontinence are significant

For 2008–09, the health care expenditure estimated for incontinence was \$201.6 million (not including residential aged care costs). In comparison, the equivalent expenditure for 2003 was \$157.9 million (in 2008-09 dollars). The largest share of the expenditure in 2008-09 was for admitted patient hospital services, which accounted for \$145.5 million, or 72% of the total health care expenditure that could be allocated to incontinence. The Continence Aids Assistance Scheme and out-of-hospital medical services were the next largest contributors to the cost, at \$31.6 million and \$17.7 million respectively. Additional costs not included in these estimates are personal costs, such as laundry, clothing and time.

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Introduction

Incontinence is a considerable problem for Australians. It affects people's ability to engage in education, employment and social situations. Incontinence is a considerable burden for people with disability as well as for the people who care for them. It is costly, for both people with incontinence and government programs, to support those people.

This bulletin follows on from a report released by the Australian Institute of Health and Welfare (AIHW) in 2006, which reported on information about incontinence in Australia drawn from the Survey of Disability, Ageing and Carers (SDAC) conducted by the Australian Bureau of Statistics (ABS) in 2003. This bulletin provides brief findings on incontinence in Australia from the next iteration of the SDAC, which was conducted in 2009. It will be followed by a more detailed report to be released in 2013. A summary of the ABS 2009 SDAC data quality declaration can be viewed via the link: <<http://bit.ly/10fZbDb>>.

The 2013 report will include more detailed analysis of carers of people who suffer from incontinence, information on the burden of incontinence on the Australian population, and an update on the development of Australian continence data standards, first included in the 2006 report. Some components of expenditure on incontinence (largely residential aged care costs) have not been included in this bulletin, as the information is not currently available for 2008–09.

It should be noted that the SDAC is a sample survey and therefore sampling errors are associated with all estimates. Issues of statistical significance are highlighted, where relevant.

Australian Government initiatives

This bulletin and the forthcoming more detailed report have been commissioned by the Australian Government Department of Health and Ageing to provide the most up-to-date data and information on the prevalence and costs of incontinence in Australia. The SDAC has been used for this data analysis as it is the best source of detailed information on incontinence in Australia and it complements the increasing number of studies that paint a picture of the experience, prevalence and treatment of incontinence.

Since 2006 the Australian Government has continued to support the prevention and management of incontinence through two complementary initiatives: the National Continence Program (NCP), and the Continence Aids Payment Scheme (CAPS), which replaced the Continence Aids Assistance Scheme in 2010. The NCP was initiated in 2011 and builds on the National Continence Management Strategy that was established in 1998. It supports a number of activities, including World Continence Week, the annual National Conference on Incontinence, the National Continence Helpline, the National Public Toilet Map and the Bladder Bowel website. The CAPS aims to help people with permanent and severe incontinence to meet some of the costs of their incontinence products.

Definition and measurement

Information about incontinence is limited by aspects of definition and measurement. The definition of incontinence is to some extent a matter of degree. A person reporting mild incontinence may have the same symptoms as another person who does not report incontinence. This is for a number of reasons, including the degree of inconvenience resulting from incontinence; the need for assistance with toileting; and the degree of embarrassment experienced. It is likely that a person's embarrassment may result in them being more likely to consider that they are affected by incontinence. Conversely, embarrassment may hinder a person from identifying the problem in a survey.

Some of the differences in prevalence and experience of incontinence between people in the community and people in cared accommodation are presented in this bulletin.

Outline

This bulletin is presented in four sections:

1. Approaches to defining and measuring incontinence, along with the problems encountered with this activity
2. Summary information from studies, in Australia and overseas, on the prevalence of incontinence
3. Analysis from the 2009 SDAC on the experience of incontinence
4. Expenditure on incontinence.

There are financial costs to incontinence as well as personal costs. In the last section, potential expenditure on incontinence is described where it could be identified. Community financial costs can usually be identified, but personal costs may be unaccounted despite the burden they may place on individuals and their families. There are limitations to the information that provides the basis for estimated expenditure on incontinence. An estimated expenditure on management of incontinence in residential aged care settings is not yet available for 2008–09; as well, many incontinence costs are not reported separately from broader costs of care, and incontinence is not always recorded as an additional diagnosis for patients with another primary diagnosis.

Definition and measurement of incontinence

Definitions of incontinence

Definitions of incontinence in research and policy reports are diverse. However, all of them are based on the presence of involuntary leakage of urine or fecal matter, including the definition derived by the International Continence Society (Milsom et al. 2009). Norton et al. (2006) suggest that the definition of incontinence also includes the social or hygienic elements of the problem.

Debate about the volume or frequency of incontinence episodes or leakage, and the extent to which incontinence is problematic, introduces uncertainty in the definition. There are no clear boundaries between mild incontinence and continence; the boundary between continence and incontinence may be a matter of degree. For instance, Sansoni et al. (2006) reports that many people in the community experience uncomfortable feelings of urgency without reporting episodes of incontinence.

Anal incontinence is distinguished from fecal incontinence in so far as it includes the involuntary leakage of flatus (Milsom et al. 2009). Many studies of incontinence exclude leakage of flatus (for example, Hawthorne 2006).

Types of incontinence

The main distinction made between different kinds of incontinence is between urinary and fecal or anal incontinence. Further distinctions are made on the basis of a number of characteristics.

It is more common to distinguish between different kinds of urinary incontinence than kinds of fecal incontinence, but the following characteristics are sometimes used to distinguish different kinds of fecal incontinence as well as urinary incontinence:

- the frequency of incontinence episodes (Staskin et al. 2009)
- the volume of matter voided (Staskin et al. 2009)
- whether incontinence is a result of a sudden, irresistible urge, or the result of stress arising from such events as coughing, laughing or lifting heavy objects, or a combination of urge and stress incontinence (Abrams et al. 2002)
- associated effects and features of incontinence such as waking in the night to void (nocturia) (Nijman et al. 2005)
- other characteristics that interfere with toileting such as mobility impairment (Offermans et al. 2009) or dementia (Goode et al. 2010)

Measurement of severity

Severity of incontinence usually takes into account the frequency of urination or defecation, or the volume or amount of loss. The embarrassment or inconvenience of incontinence is sometimes also taken into account, sometimes using severity indices and quality of life scales to correlate with quantitative measures (for example, Bordeianou et al. 2008).

Definitions of incontinence vary across studies. One reason for this is the setting (for example, clinical settings and community settings) of the study. The setting affects the method of data collection on incontinence being employed, and thus the type and precision of information collected that are used to build these definitions. Clinical settings often give rise to definitions that rely on direct observations or relatively precise measures of volume (and sometimes frequency). For instance, studies of the treatment of female urinary incontinence may include direct measurement of urinary incontinence (Haylen et al. 2010).

By contrast, in community settings, data may be collected by means of surveys of incontinence sufferers. In these settings, definitions of incontinence are based on reporting by sufferers or their carers. These usually include less precise reporting of volume and frequency, and also occasionally indications of inconvenience, embarrassment or bother (for example, Rockwood 2004). Such studies are more likely to contribute to an understanding of people's experience of incontinence but they may also be less precise or objective in identifying the quantitative severity of incontinence (Hawthorne 2006).

The most commonly used index of incontinence severity is the Incontinence Symptom Severity Index, used in measuring severity of urinary incontinence (Sandvik et al. 2000, Milsom et al. 2009). This index measures both the frequency of leakage and the amount of urine lost. The Wexner Continence Grading Scale is commonly used in measuring severity of fecal incontinence, often modified to exclude loss of flatus (Hawthorne 2006).

Prevalence rates and risk factors from the literature

Key findings

Urinary incontinence

- The prevalence of urinary incontinence increases as people age.
- Women are more likely to experience symptoms of urinary incontinence than men.
- For men, urinary incontinence is highest after the age of 80.
- For women, the prevalence of urinary incontinence tends to increase substantially from 50 years onwards.
- Numerous risk factors are associated with urinary incontinence (for example, age, sex, pregnancy, obesity, lower urinary tract symptoms, diabetes mellitus).

Fecal incontinence

- Fecal incontinence affects a smaller proportion of the population than urinary incontinence.
- The prevalence of fecal incontinence increases as people age; it is at its highest for both men and women after the age of 80.
- There is no substantial difference in prevalence rates between men and women.
- Besides the age effect, evidence for associations with other risk factors is limited.

Large variation in prevalence estimates

Prevalence estimates vary greatly between studies due to a number of factors:

- Variation in definitions and measurement—there is no consistent qualitative distinction between continence and incontinence.
- Variation in methodology—data collection methods vary (for example, questionnaire versus face-to-face interviews), participant inclusion and exclusion criteria vary, and the type of incontinence studied varies.

- Limitation due to self-report—given the sensitive nature of the topic, studies solely reliant upon self-report data may underestimate the true prevalence rates.
- Sampling and non-response issues—this may be due to the sensitive nature of the topic, or a belief that the problem is not serious enough to report it (Milsom et al. 2009).

The following section is a summary of the prevalence estimates from literature dated 2006 onwards (except the *South Australian Health Omnibus Survey* (SAHOS) which was conducted in 2004 and reported on by Hawthorne in 2006), with reference to recently published reviews (Shamliyan et al. 2009; Botlero et al. 2008; Shamliyan et al. 2007; Pretlove et al. 2006). These studies include people with mild to moderate symptoms of incontinence. For information on studies published before 2006, see *Australian incontinence data analysis and development* (AIHW 2006).

International prevalence estimates

The majority of current research focuses on urinary incontinence in the community (that is, people who are not in cared accommodation) and women. However, an increasing number of studies present data on fecal incontinence and incontinence in men. There is limited research about urinary and fecal incontinence for people living in institutions or long-term care. Many studies come from the United States, but literature is available from Europe and Asia.

Urinary incontinence

Buckley and Lapitan (2010) presented a review of the best available evidence regarding urinary incontinence prevalence estimates for the Fourth International Consultation on Incontinence. The studies canvassed the full spectrum of prevalence estimates for ‘any’ leakage or incontinence, ranging from:

- For women:
 - Aged 20–39: 7–37%
 - Aged 40–59: 31–48%
 - Aged 60–79: 30–61%
 - Aged 80 and over: 37–63%.

The figures for 20–39 year old women represent the full range of prevalence data for females in this age group, including values far from most other values in the data set (known as outliers). All other ranges for urinary incontinence prevalence rates presented by Buckley and Lapitan (2010) exclude outliers.

- ♦ For men:
 - Aged 20–39: 2.0–2.4%
 - Aged 40–59: 2–19%
 - Aged 60–79: 3–23%
 - Aged 80 and over: 8–22%.

Compared to prevalence estimates for ‘any’ leakage or incontinence, prevalence estimates for daily incontinence ranged less widely. Buckley and Lapitan (2010) reported that in women aged 60 or younger estimates were less than 25%. In comparison, for women older than 60 the estimates ranged from 9 to 39%. For men, the estimate of daily incontinence ranged from 2 to 11%.

There is strong evidence supporting a sex and age effect for urinary incontinence. Studies consistently show that the prevalence of urinary incontinence in women is higher than for men, for all age groups (Markland et al. 2011; Hawthorne 2006). They also show that as people age the prevalence of urinary incontinence increases (Whitehead et al. 2010; Buckley and Lapitan 2010; Botlero et al. 2009; Shamliyan et al. 2007).

Fecal incontinence

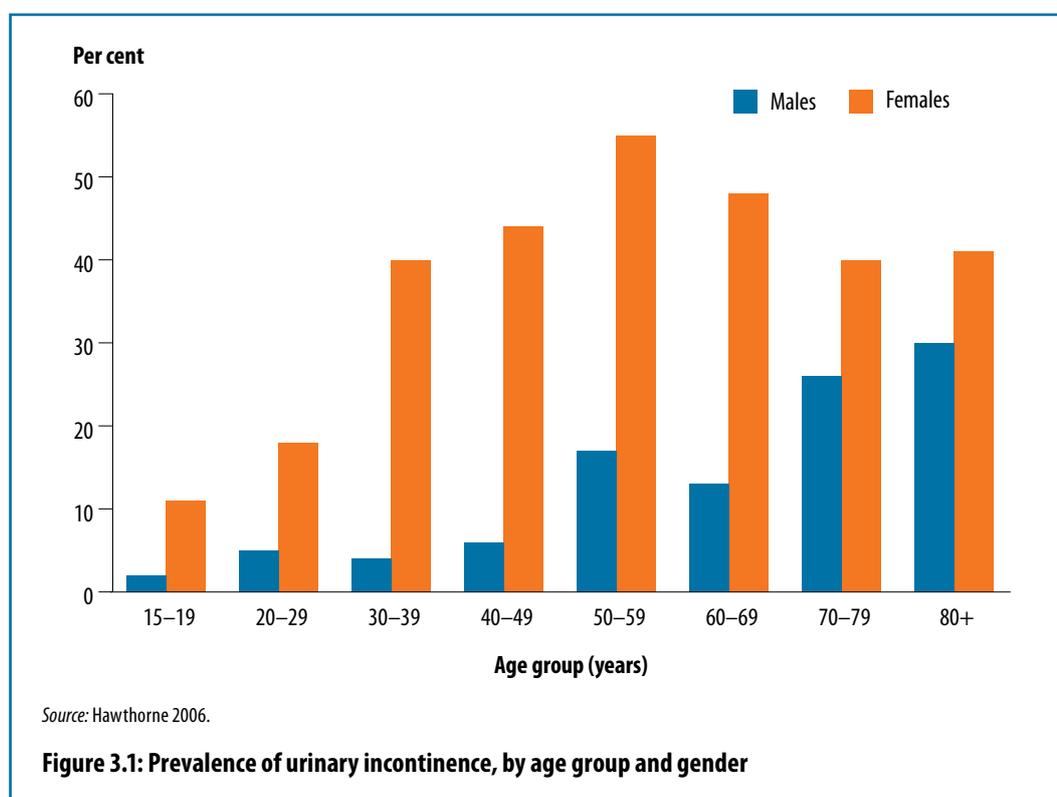
Fecal incontinence is less prevalent than urinary incontinence. A large international systematic review reported that the prevalence of fecal incontinence in men was less than 10% in all age groups (Shamliyan et al. 2007). For men aged 45–64 the prevalence was 6.4%, compared with 9.6% in men aged 80 and over. The same review also reported that the prevalence in women increased from 7.3% in women aged 45–64, to 9.5% for women aged 80 and older.

The difference in fecal incontinence prevalence estimates between males and females was less pronounced than for urinary incontinence. Although recent studies found that more women reported fecal incontinence than men, these differences were not substantial.

Australian prevalence estimates

Urinary incontinence

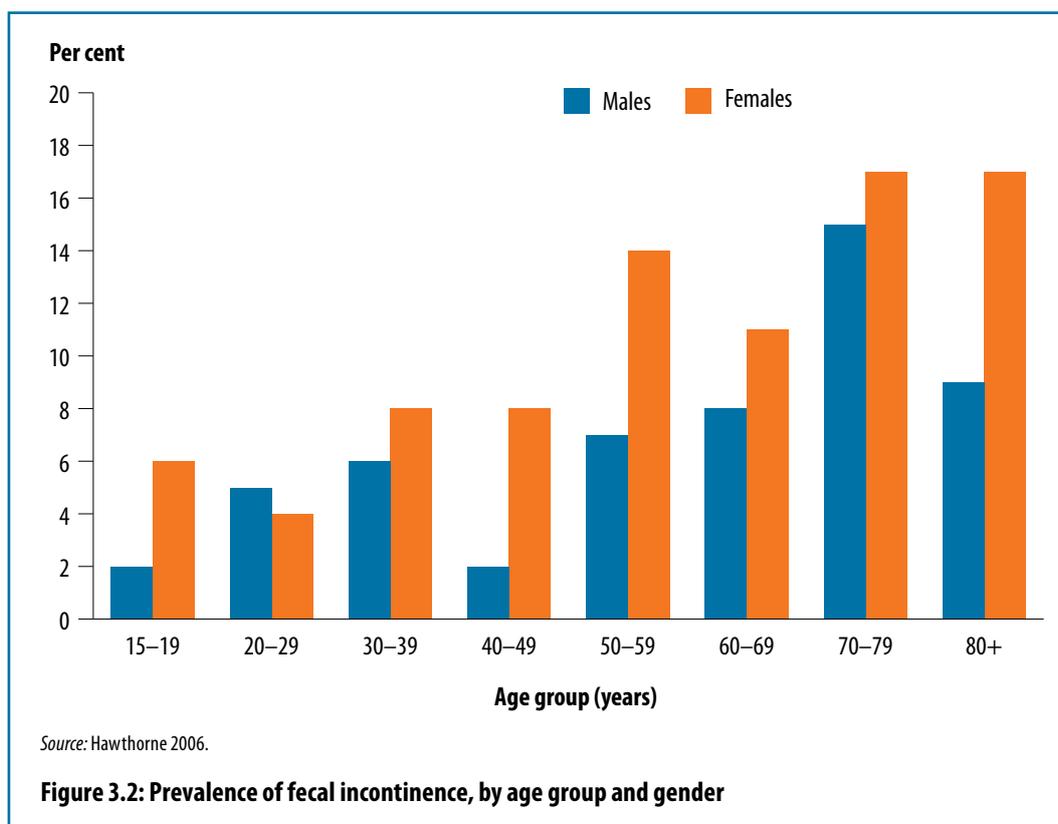
Figure 3.1 shows the prevalence of urinary incontinence in Australia from the SAHOS (2004) study. A clear gender effect is evident particularly in the younger age groups, where more females tend to report symptoms of urinary incontinence than males. As people age, this gap closes substantially. The highest prevalence for females (55% for females aged 50–59), reported in this study, differed from international-based studies which generally reported highest prevalence at older ages (Shamliyan et al. 2007). For males, the highest prevalence was for those aged 80 or older (30%).



From the literature reviewed, age and gender are the most commonly cited associated risk factors for urinary incontinence. Both international and Australian studies demonstrate that the prevalence of urinary incontinence increases as people age. Also, females of all ages have a higher prevalence of urinary incontinence than males (Markland et al. 2011; Buckley and Lapitan 2010; Milsom et al. 2009; Shamliyan et al. 2009; Botlero et al. 2008; Shamliyan et al. 2007; Anger et al. 2006a; Anger et al. 2006b; Hawthorne 2006).

Fecal incontinence

Figure 3.2 shows the prevalence of fecal incontinence in the Australian population, from the SAHOS (2004) study. Females had a higher prevalence of fecal incontinence than males in all age groups except for 20–29 year olds, where the prevalence estimates were similar. For males, the prevalence of fecal incontinence rose steadily between the ages of 40–79, then fell quite sharply at age 80 years and above. For females the prevalence peaked at 50–59, and again at 70 and above.



Similar to urinary incontinence, the literature supports an age effect for fecal incontinence, with the prevalence increasing as people age. However, a gender effect for fecal incontinence is less defined, with some studies reporting higher prevalence rates for females, but this difference was not significant (Rey et al. 2010; Markland et al. 2009; Milsom et al. 2009; Whitehead et al. 2009; Shamliyan et al. 2007; Hawthorne 2006; Pretlove et al. 2006; Varma et al. 2006).

Other risk factors associated with incontinence

Because of the cross-sectional nature of most studies, it is difficult to ascertain factors that may cause incontinence. However, there is research identifying possible risk factors associated with incontinence.

Along with the age and gender effects described earlier, other risk factors commonly cited in the literature include:

- **Pregnancy, childbirth and parity (the number of times a woman has given birth):** Buckley and Lapitan (2010) report prevalence rates of between 32–64% for all urinary incontinence and 40–59% for stress or mixed urinary incontinence during pregnancy. Urinary incontinence, particularly stress urinary incontinence, increases from 7% before pregnancy to 31% during pregnancy for women who have never given birth, and from 24% to 42% in women who have previously given birth one or more times (Buckley and Lapitan 2010). Vaginal deliveries have been associated with urinary incontinence, but associations with fecal incontinence are less clear (Milsom et al. 2009).
- **Obesity:** Subak et al. (2009) found that for every 5-unit increase in body mass index there is a 20–70% increase in the risk of daily urinary incontinence. It was proposed that the added weight of the person increases the abdominal pressure, leading to pelvic muscle weakness. There is some evidence to suggest that obesity is a modifiable risk factor for fecal incontinence (Milsom et al. 2009).
- **Prostate cancer, prostate disease and prostate surgery:** men with either prostate disease or prostate cancer had increased risk of urinary incontinence. Additionally, men who underwent prostate surgery were at increased risk of urinary and fecal incontinence (Shamliyan et al. 2007; Milsom et al. 2009; Shamliyan et al. 2009).
- **Other factors:** across the studies, associations have been found between incontinence and the following factors:
 - lower urinary tract symptoms and infections in women
 - diabetes mellitus
 - cognitive impairment and dementia
 - menopause
 - neurological disorders
 - poor general health
 - chronic illness
 - mobility impairment
 - limitations in daily activities.

However, the evidence for these associations is limited at this stage.

Experience of incontinence

Key findings

- As defined in the *2009 Survey of Disability, Ageing and Carers (SDAC)* an estimated 316,500 people experienced severe incontinence. The corresponding number in 2003 was 284,500—the difference between 2003 and 2009 was not statistically significant.
- In 2009, 144,300 people always needed assistance with bladder or bowel control.
- Of the 139,000 people living in households who always or sometimes needed assistance to manage their bladder or bowel control, 46.2% received informal assistance for self-care only, 10.7% received formal assistance for self-care only and 28.1% did not receive any self-care assistance.
- In 2009, 195,800 people used continence aids. Of this population, 99,700 (50.9%) people lived in cared accommodation. The others (96,100 or 49.1%) were people aged 10 or over living in households.
- For people living in households with severe incontinence, the most common main condition was 'musculoskeletal conditions' (27.7%). For people living in cared accommodation the most common main condition was dementia (including Alzheimer disease) (34.0%).
- The labour force participation rate was considerably lower for people aged 15–64 who always or sometimes needed assistance with managing bladder or bowel control (20.4%) when compared with people who had difficulty but did not need assistance with managing bladder or bowel control (42.3%) and people who had no difficulty at all (56.8%).
- A higher proportion of primary carers who usually assisted with managing incontinence reported a physical or emotional change (49.6%), feeling weary and lacking energy (45.0%) or being worried or depressed (39.5%) compared with those who did not usually assist with managing incontinence (30.4%, 30.2% and 28.7% respectively).

This section presents an estimate of the Australian population with 'severe' incontinence, and describes some experiences of these people and their carers. A person with severe incontinence is defined as someone who always or sometimes needs assistance with managing their bladder or bowel control and/or uses continence aids. This population is a subcategory of the total population who experience incontinence. It is an under-estimate of the total prevalence of incontinence in Australia as it does not include people with milder symptoms of incontinence.

The primary data source for analysing the experience of incontinence is the 2009 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC). This national population-based survey comprised over 73,000 people including those living in private households, non-private residences (for example, hotels, boarding houses) and cared accommodation (living in facilities such as hospitals and nursing homes for three months or more). It excluded people living in correctional institutions. A statistical process known as 'weighting' was conducted to adjust the results from the sample to infer results for the total Australian population. Information was collected from people living in both urban and rural areas in all states and territories, but not people living in very remote areas of Australia.

The 2009 SDAC defines 'disability' as the presence of one or more of 17 limitations, restrictions or impairments which lasted, or was likely to last, for six months or more and restricted everyday activities (see Box 4.1). The 2009 SDAC also defines specific concepts and terms in relation to incontinence, continence aids and self-care assistance (see Box 4.2). This survey does not allow for the differentiation between urinary and fecal incontinence.

Box 4.1: 2009 SDAC definition of 'disability'

In the SDAC, a person has a disability if they experienced any one of the following limitations, restrictions or impairments and a restriction in everyday activities:

- Loss of sight (not corrected by glasses or contact lenses)
- Loss of hearing with restricted communication or the use of aids
- Speech difficulties
- Chronic or recurrent pain or discomfort causing restriction in everyday activities
- Shortness of breath or breathing difficulties causing restriction
- Blackouts, fits or loss of consciousness
- Difficulty in learning or understanding
- Incomplete use of arms or fingers
- Difficulty gripping or holding things
- Incomplete use of feet or legs
- Nervous or emotional condition causing restriction
- Restriction in physical activities or in doing physical work
- Disfigurement or deformity; in SDAC, people with disfigurement or deformity are often excluded from further analyses of disability.
- Mental illness or condition requiring help or supervision
- Long-term effects of head injury, stroke or other brain damage causing restriction
- Receiving treatment or medication for any other long-term condition or ailment, and still restricted
- Any other long-term condition resulting in restriction.

In the previous *Australian incontinence: data analysis and development* report (AIHW 2006), people with incontinence, people with a need for assistance with managing bladder or bowel control and people who use continence aids are referred to as 'people with disability with incontinence'. However, in this bulletin, for clarity, these people are referred to simply as 'people with incontinence'.

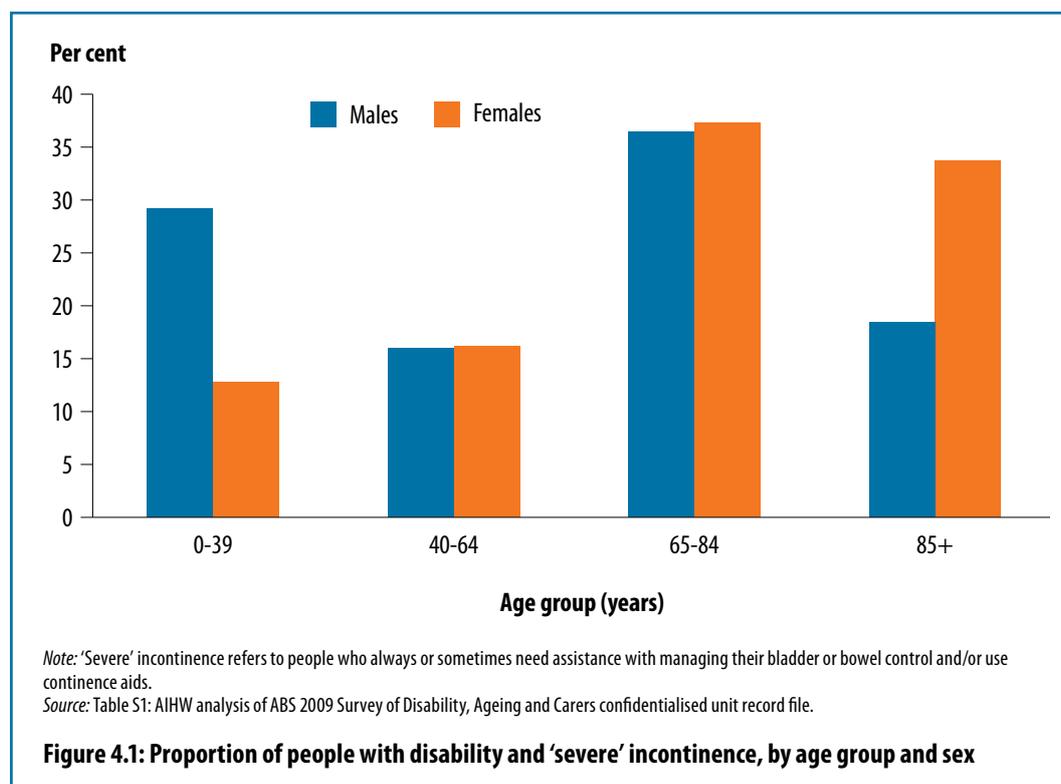
Population with 'severe' incontinence

In 2009, as defined in SDAC, an estimated 316,500 people experienced severe incontinence:

- ✦ 209,000 (66.0%) were female (see Figure 4.1 for further breakdowns).
- ✦ 195,300 (61.7%) lived in households.
- ✦ About 144,300 (45.6%) always needed help or supervision with bladder or bowel control.
- ✦ Another 111,400 (35.2%) sometimes needed help or supervision.

An additional 328,100 people reported having difficulty with bladder or bowel control but did not need assistance.

Of the two numbers presented in the *Australian incontinence: data analysis and development* report (AIHW 2006) only the figure of 284,500 people suffering from severe incontinence based on SDAC data is comparable with the figure of 316,500 people presented above. In this earlier report, a higher figure of 545,000 people suffering from severe and/or frequent incontinence was based on analysis of the 2004 SAHOS in conjunction with the analysis of the 2003 SDAC specifically for the burden of disease analysis. Information on the burden of incontinence on the Australian population will be presented in the upcoming more detailed report on incontinence to be released by AIHW in 2013, once the analysis has been completed.



Box 4.2: SDAC concepts and terms

Assistance with bladder or bowel control

The survey asks respondents whether they needed assistance with bladder or bowel control. This analysis cannot differentiate between the need for assistance with bladder control and the need for assistance with bowel control.

'Self-care' assistance

In SDAC 2009, 'self-care' assistance refers to help or supervision with bathing/showering, dressing, eating, toileting or managing bladder or bowel control. It is not possible to identify people who receive assistance with managing bladder or bowel control only.

Continence and toileting aids

The term 'aids and equipment' is defined in SDAC 2009 as 'any device used by persons with one or more disabilities to assist them with performing tasks, but does not include help provided by another person or an organisation'. Continence aids include absorbent pads and briefs, urinary appliances, waterproof pants and specialised bed linen. Toileting aids include commodes, toilet frames and toilet chairs.

Assistance with bladder/bowel control versus assistance with toileting

It is possible for a person to need assistance with toileting but not need assistance with bladder or bowel control. For instance, a person with a physical disability may need assistance getting to the toilet or sitting on the toilet but they do not need assistance with managing their bladder or bowel control (that is, functional incontinence).

Assistance and the use of continence aids

Need for personal assistance

According to SDAC 2009, of the 144,300 people who always needed help or supervision with bladder or bowel control, 64,800 (44.9%) lived in households compared with 79,600 (55.1%) who lived in cared accommodation. Of those living in households:

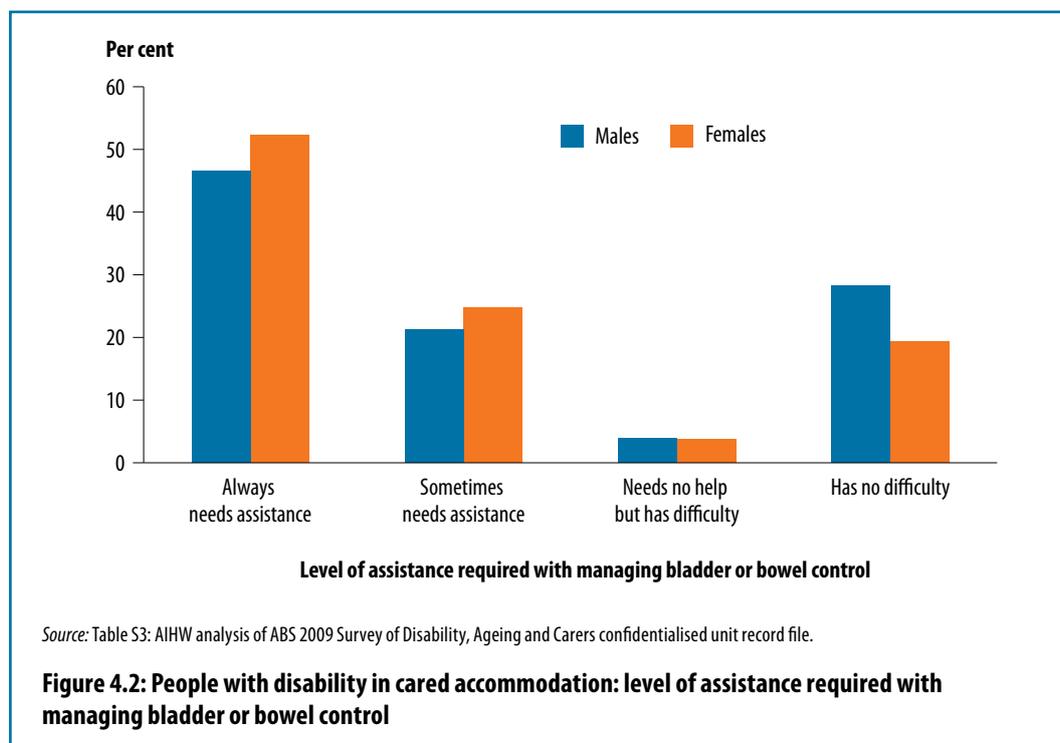
- More than half were female (35,000 or 54.0%).
- About 1 in 3 were aged 0–19 (20,900 or 32.2%).

The high proportion of people living in households aged 0–19 who always needed assistance may reflect the high rate of nocturnal enuresis (bed-wetting) in this age group—with one in five children wetting the bed (DoHA 2010a).

Of those living in cared accommodation settings:

- More than two in three were female (55,800 or 70.1%)
- More than half were aged 85 and over (42,400 or 53.2%).

Among people who sometimes needed assistance with bladder or bowel control, 74,200 (66.6%) lived in households and 37,200 (33.4%) lived in cared accommodation. More than half of those in households (59.0%) and cared accommodation (71.0%) were female.



For those living in households, the proportion that sometimes needed assistance with bladder or bowel control was substantially higher for people aged 70–84 (25.0%) than for those aged 85 and older (13.4%). In contrast, for people living in cared accommodation, the proportion sometimes requiring assistance rose from 33.3% for people aged 70–84 to 55.9% for those aged 85 and over. This supports the notion that the need for assistance with bladder or bowel control contributes to the decision for older people to move to cared accommodation (Pearson et al. 2002).

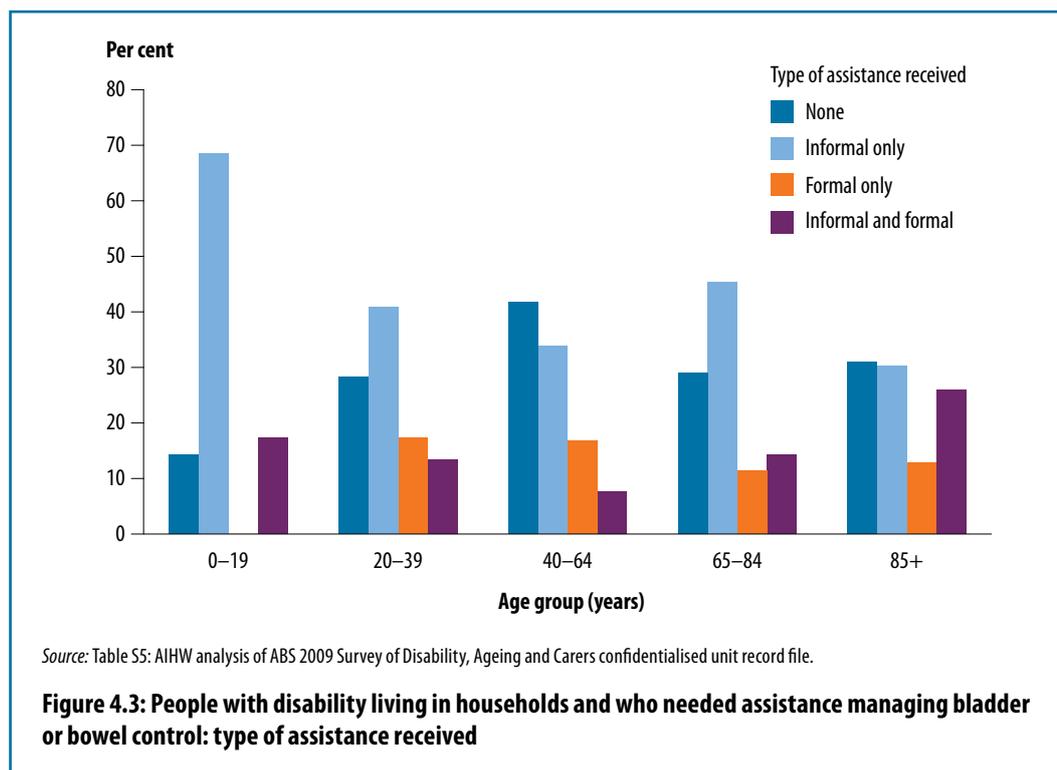
A substantially higher proportion of people living in households did not need help but had difficulty with their bladder or bowel control (322,200 people or 8.5%), compared with those living in cared accommodation (5,900 or 3.8%) (Figure 4.2).

Assistance received for self-care

SDAC 2009 allows the identification of people living in households who needed assistance with managing their bladder or bowel control and who received assistance with self-care. There were 139,000 people living in households who always or sometimes needed assistance to manage their bladder or bowel control. Many of these people rely upon assistance from informal carers (that is, unpaid help such as family members) to assist them with self-care. Others receive formal assistance from an organised service (that is, paid help) (Figure 4.3). Of this population:

- Almost half (46.2%) received informal assistance for self-care only, compared with about 1 in 10 (10.7%) who received formal assistance for self-care only.

- About 1 in 7 (15.0%) received both informal and formal self-care assistance.
- About a quarter (28.1%) did not receive any self-care assistance. In comparison, in 2003, 15.9% reported they did not receive any self-care assistance. This difference was not statistically significant.



A substantial number of people living in households needed informal assistance to manage their bladder or bowel control but were not receiving it (53,900 or 38.8%). For those who needed this kind of assistance and were receiving it, the frequency was high:

- 40,600 (29.2%) were receiving informal assistance 3 to 6 times a day.
- 25,500 (18.4%) were receiving informal assistance 1 to 2 times a day.

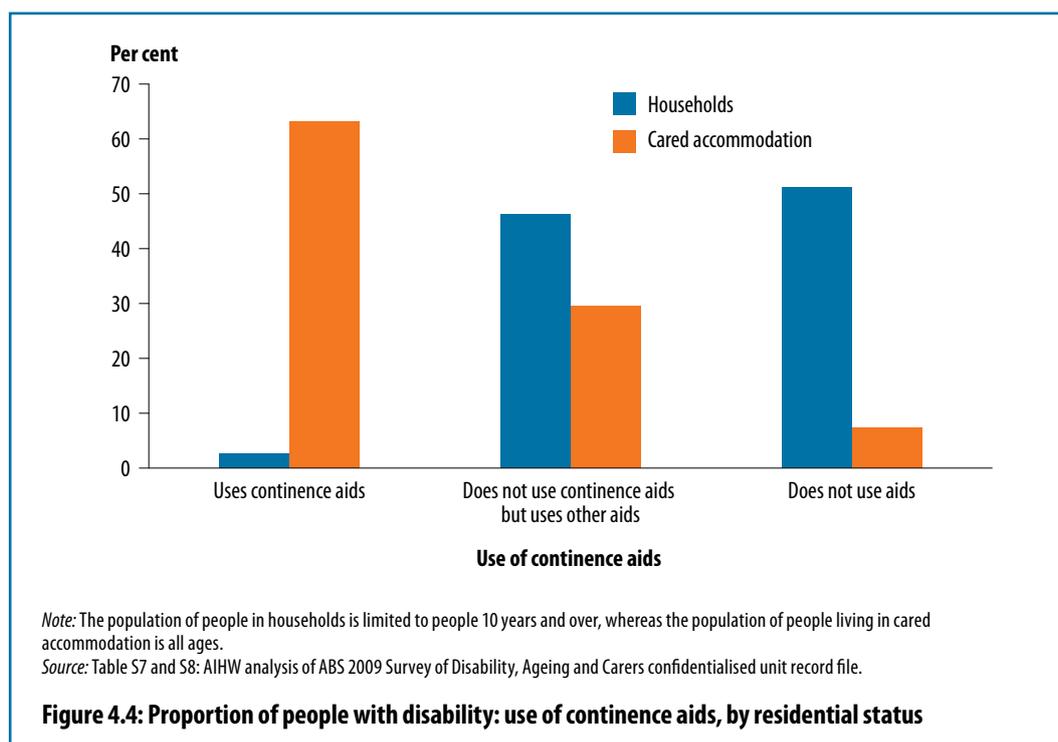
The majority of people living in households who needed formal assistance with managing bladder or bowel control received this kind of assistance less than once a year (103,300 people or 74.3%). However, there was a smaller group of people who received formal assistance quite regularly:

- 12,000 (8.6%) receive self-care assistance 1 to 6 times a week.
- 8,500 (6.1%) receive self-care assistance once or twice a day.
- 6,600 (4.7%) receive self-care assistance 3 to 6 times a day.

Use of continence aids

About 96,100 people aged 10 and over living in households, or 2.7%, used continence aids, irrespective of their level of incontinence (see Box 4.2) according to SDAC 2009. In comparison, 83,800 (2.4%) of people aged 10 and over living in households used continence aids in 2003 (AIHW 2006)—this was not significantly different to the 2009 proportion of 2.7%. Of the people in households who used continence aids in 2009, three in four (73.2%) were female.

A much higher proportion of people living in cared accommodation reported using continence aids (99,700 people or 63.2%) when compared with households (Figure 4.4)—the 2009 SDAC data for cared accommodation included people aged under 10. Just as in households, females in cared accommodation were the more common users of continence aids, representing 71.5% of users. It is difficult to compare the 2003 and 2009 data for people in cared accommodation due to the different age ranges in the analyses—children under 10 were included in the cared accommodation population for 2009 but not in 2003.



According to SDAC 2009, of people aged 10 and over living in households, 7.1% of those aged 85 or older and 3.9% of people aged 65–84 used continence aids. This was in marked contrast with people in cared accommodation, of whom 66.1% aged 85 or older and 63.7% aged 65–84 used continence aids.

Need for assistance with toileting

Needing assistance to manage bladder or bowel control is different from needing assistance with toileting. For instance, a person may have no difficulty with managing bladder or bowel control, but still need assistance with getting to the toilet.

According to SDAC 2009, for people living in households who always need assistance with toileting:

- Two in three (62.8%) always need assistance with managing bladder or bowel control.
- A small proportion (6.1%) reported sometimes needing assistance with bladder or bowel control.

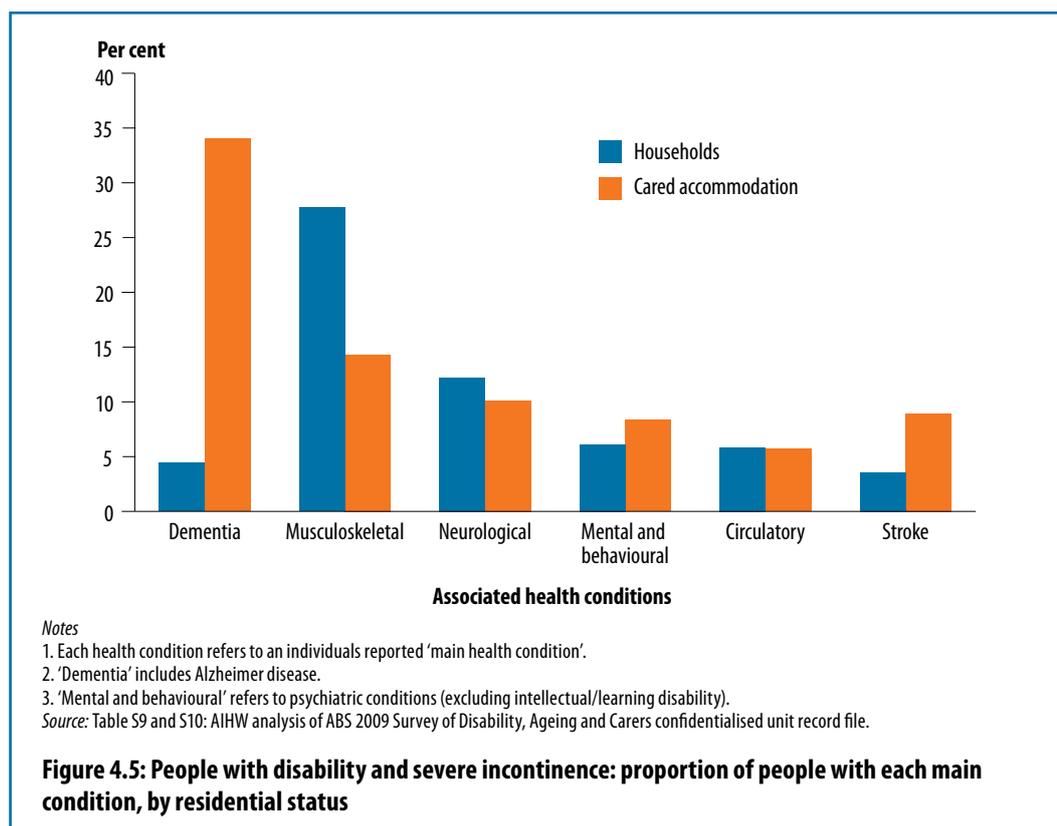
For people living in cared accommodation who always needed assistance with toileting:

- Four in five (79.3%) always needed assistance with managing bladder or bowel control.
- One in six (16.6%) sometimes needed assistance.

Of the 62,900 people living in households who always needed assistance with toileting, more than one in four (27.8%) had no difficulty with managing bladder or bowel control. Similarly, of the 60,400 people living in households who sometimes need assistance with toileting, 61.5% did not need assistance with managing bladder or bowel control.

Associated health conditions

In SDAC 2009 some people reported suffering from more than one health condition; in this case they also indicated which of these was the main condition. The following analysis looks at the main health condition reported by people with severe incontinence. Due to the infrequency of many health conditions, these have been grouped together using the ICD-10-AM (International statistical classification of diseases and related health problems, tenth revision, Australian modification) in most instances (National Centre for Classification in Health 2010).



As shown in Figure 4.5, for people with severe incontinence living in households, the most common main condition was 'musculoskeletal conditions' (including arthritis and related disorders and back problems) (27.7%). Neurological conditions (including Parkinson disease, multiple sclerosis and epilepsy), mental and behavioural (intellectual/learning) and mental and behavioural (psychiatric) were also reported by a substantial proportion of people with severe incontinence, living in households (12.2%, 9.5% and 6.1% respectively).

Unlike for people living in households, the most common main condition associated with severe incontinence for people living in cared accommodation was dementia (including Alzheimer disease) (34.0%) (see Box 4.3)¹. Around 14.3% of people in cared accommodation with severe incontinence reported musculoskeletal conditions and another 10.1% reported neurological conditions. Stroke was also commonly associated with severe incontinence in this population (8.9%).

Box 4.3: Dementia and incontinence

Incontinence is a common problem for people with dementia (especially for those in the later stages of the condition). People with dementia may have trouble with 'holding on', finding the toilet, knowing or remembering how to undress and pull their pants down, knowing when their bladder or bowel is empty, or being aware of the need to go to the toilet (DOHA 2010b).

According to SDAC, in 2009 there were 106,600 people with dementia¹. Of this group:

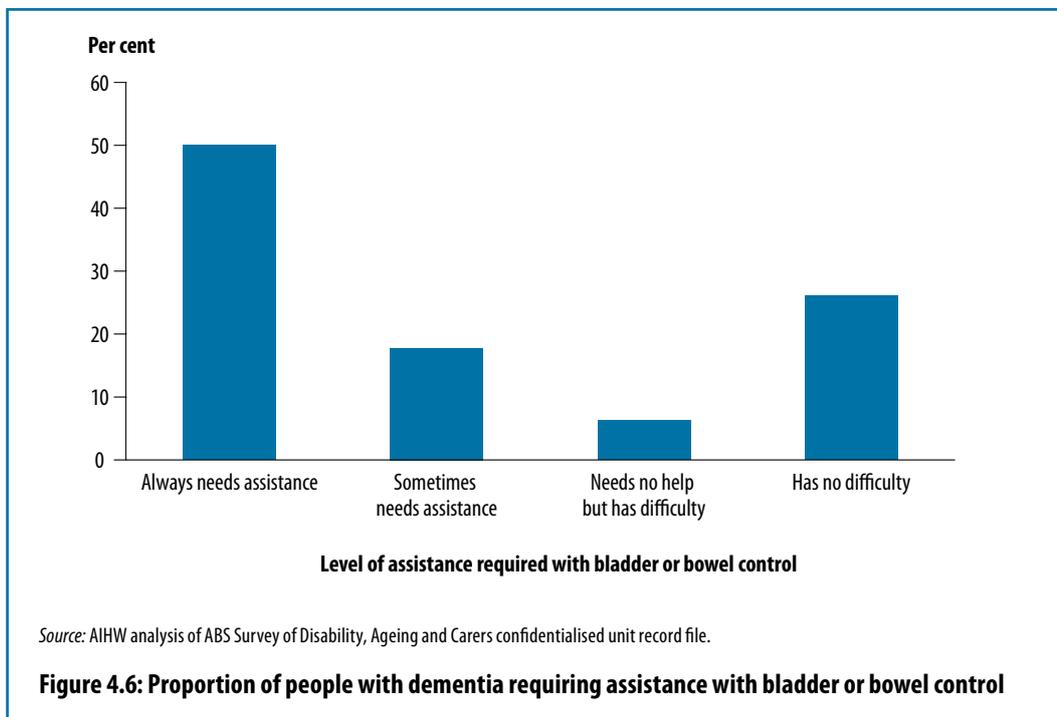
- 57,400 (53.9%) used continence aids.
- 53,300 (50.0%) always needed help or supervision with bladder or bowel control and 18,900 (17.8%) sometimes needed help or supervision (see Figure 4.6).

There were 74,900 people with dementia and severe incontinence:

- 52,000 (69.4%) were female.
- 59,400 (79.2%) lived in cared accommodation.

Managing people with dementia and incontinence places additional burden on carers. For these people, the onset of incontinence is a key factor in the decision to seek residential care (Georges et al. 2008; Hope et al. 1998).

¹ Estimates of the number of people with dementia are based on the 2009 SDAC. These estimates differ from the estimated prevalence of dementia reported in the AIHW report on dementia, which is based on different data sources and a different methodology (AIHW 2012a).



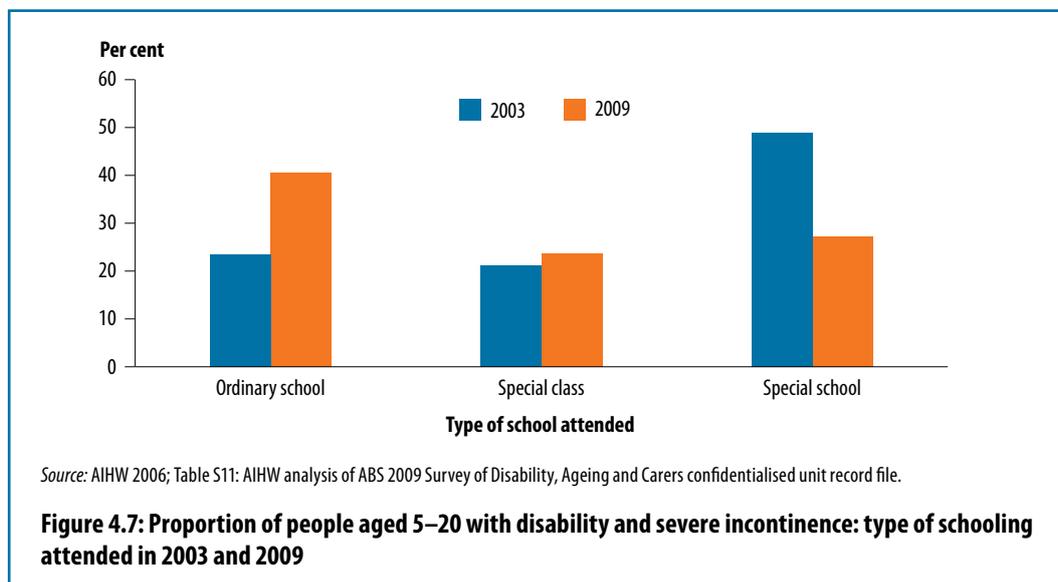
Participation

Education

Going to the toilet at school can be challenging for some children and young people, particularly those with disability. In 2009, there were 29,500 young people (that is, 5–20 years) with severe incontinence. Just over 9 in 10 of these people (91.2%) were attending school. Of those with severe incontinence, who were attending school:

- 11,900 (40.5%) were attending a mainstream school
- 8,000 (27.2%) were attending a special school
- 7,000 (23.6%) were attending a special class in a mainstream school.

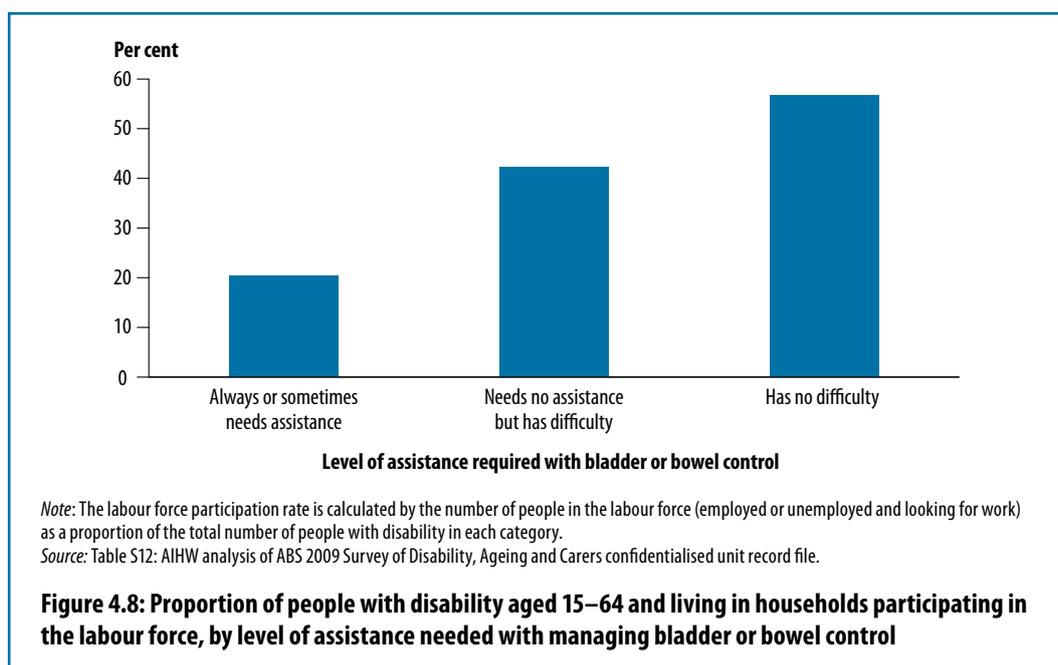
The proportion of young people with disability (without severe incontinence) attending school was 89.5%. A greater proportion of younger people with disability and severe incontinence were attending special school (27.2%) compared to young people with disability without severe incontinence (11.9%). Comparisons with proportions in 2003 are presented in Figure 4.7.



Labour force participation

Participation in the labour force patterns differed markedly for people with disability living in households depending on whether they needed assistance with managing bladder or bowel control (see Figure 4.8).

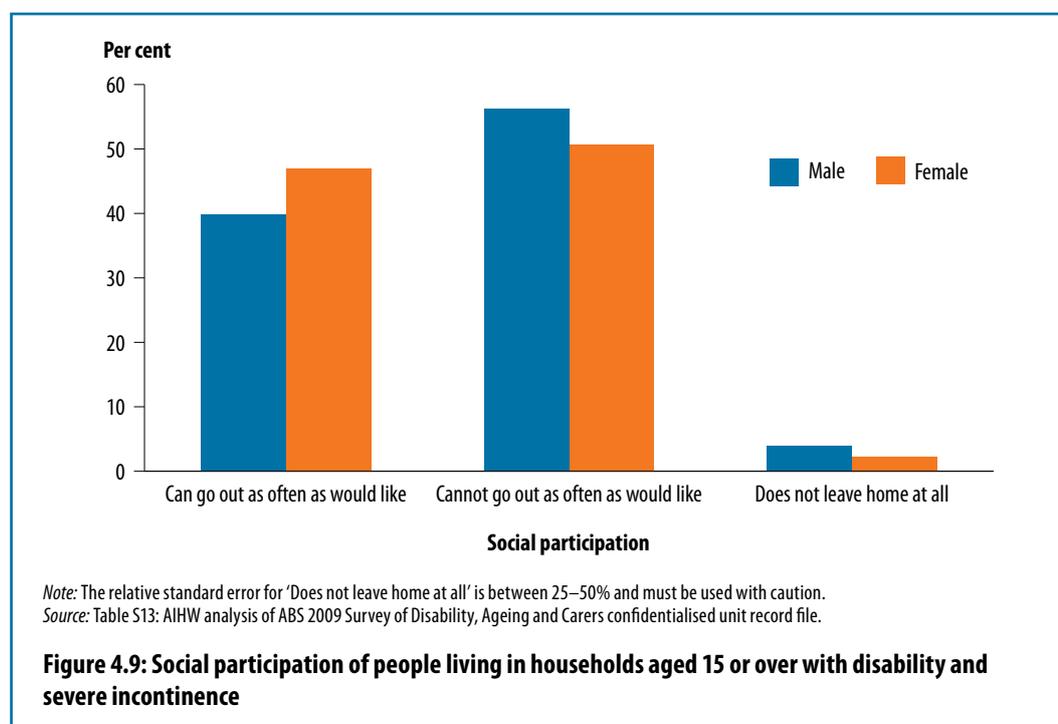
- One in 5 people (20.4%) who always or sometimes needed assistance with bladder or bowel control were participating in the labour force.
- In comparison, a greater proportion of people who needed no assistance but had difficulty with bladder or bowel control were participating in the labour force (42.3%).
- According to SDAC 2009, the labour force participation rate for people without disability (aged 15 to 64) was 83.2%.



Social participation

Embarrassment, bothersome, anxiety-provoking—these are common words used to describe the impact that incontinence can have on quality of life and social participation for both women and men (Kwong et al. 2010; Townsend et al. 2008). One way this is manifested is that an individual's ability, willingness or confidence to go out as often as they like may be affected.

Of people aged 15 or over living in households and with severe incontinence, half reported that they could not go out as often as they would like (87,100 or 52.4%). About 47.0% of females reported they could go out as often as they would like, compared with 39.9% of males—this difference was not statistically significant (see Figure 4.9).

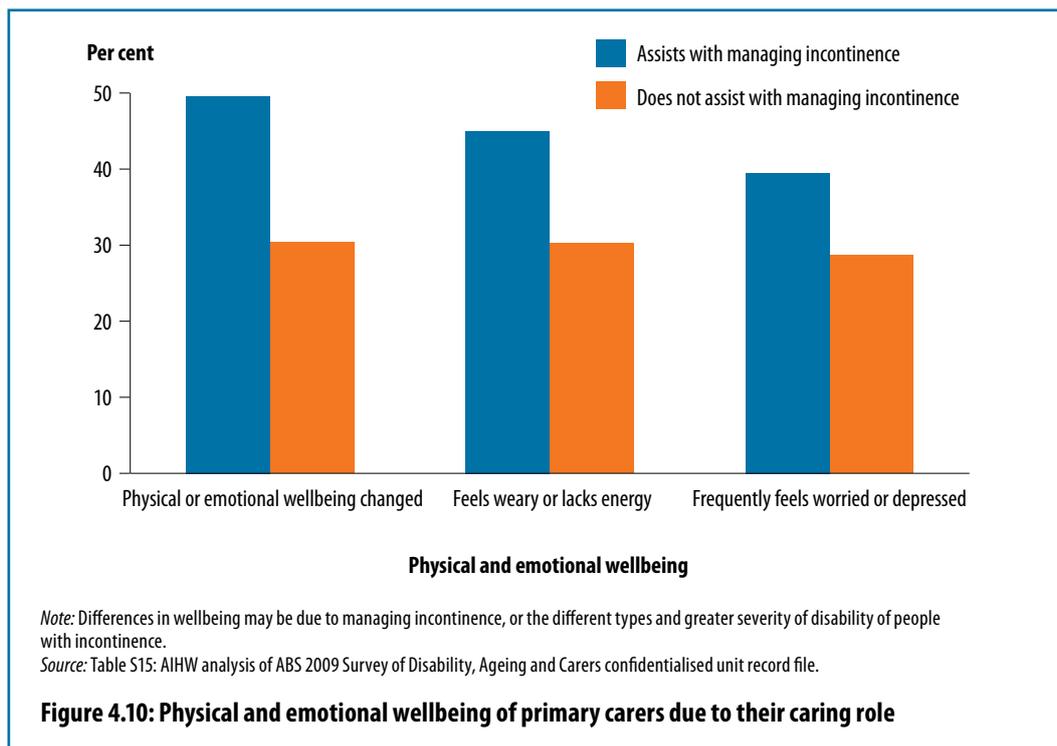


Carers

Managing incontinence places a considerable burden on primary carers and is a key factor that contributes to the decision to seek residential care for an individual (Pearson et al. 2002). It is not possible to compare the 'primary carer' data between the 2003 and 2009 SDAC because the method of identifying primary carers differed.

In 2009, there were 72,900 primary carers who usually assisted with managing another person's incontinence. Three in four of these people (73.0%) reported that they spent 40 hours or more each week actively caring or supervising. In contrast, one in three (31.1%) primary carers who did not usually assist with managing incontinence reported caring or supervising for 40 hours or more each week. The higher care needs of people with incontinence and the greater effect on primary carers may be directly due to incontinence, or the differing types and severity of disability of people who have incontinence, or a combination of both.

Providing this amount and type of care (including assistance with incontinence) has a negative impact on wellbeing for primary carers. Figure 4.10 demonstrates that a higher proportion of primary carers who usually assisted with managing incontinence reported negative effects due to their caring role, compared with primary carers who do not usually assist with managing incontinence (see Figure 4.10).



Health care expenditure for incontinence

An estimate of incontinence expenditure

There are estimated costs to incontinence as well as personal costs. Some expenditure can be estimated, such as hospital and other medical services, pharmaceuticals and continence aids, whereas some other expenditure such as laundry, clothing and time costs cannot currently be adequately estimated.

Historically, the large majority of measurable costs of incontinence has been for residential aged care: in 2003, \$1.56 billion of the total \$1.72 billion² (converted to 2008–09 prices) were for residential aged care (AIHW 2006). This information, however, is not currently available for 2008–09, as the introduction of the new Aged Care Funding Instrument for residential aged care requires the development of a new method for estimating incontinence expenditure. Information on costs of incontinence for residential aged care will be presented in the upcoming more detailed report on incontinence to be published by the AIHW in 2013.

² The continence aids costs for 2003 and 2008–09 reported in this bulletin only include the Continence Aids Assistance Scheme.

It is estimated that the monetary costs that could be allocated to urinary and fecal incontinence in Australia for 2008–09, excluding residential aged care costs, totalled \$201.6 million, which was more than non-residential aged care costs for 2003 of \$157.9 million (2008–09 prices). The costs that could be attributed to incontinence in 2008–09 were for the areas of expenditure shown in table 5.1 below.

Table 5.1: Health care expenditures for incontinence, 2008–09

Area of expenditure	Expenditure (\$million)
Admitted patient hospital services	145.5
Out-of-hospital medical services ^(a)	17.7
Pharmaceuticals requiring a prescription ^(a)	3.1
Other health services	3.8
Continence aids—Continence Aids Assistance Scheme	31.6
Total	201.6

(a) Out-of-hospital medical services and pharmaceuticals requiring a prescription are reliant on sample survey data that can vary from year to year. Time series comparisons should be treated with caution.

Note: Components may not add to total due to rounding. Expenditures listed above are total expenditures whether funded by government or by individuals.
Source: AIHW Disease expenditure database.

Hospital expenditure

Measuring expenditure on incontinence in hospitals poses challenges relating to the identification and recording of costs. These challenges include the fact that incontinence costs are often not reported separately from broader costs of care, and that incontinence is not always recorded as an additional diagnosis for patients with another primary diagnosis.

In response to these challenges, and challenges in measuring incontinence costs in other settings, the Department of Health and Ageing funded a project in 2005 on the development of a framework for the economic and cost evaluation for continence conditions. The resulting economic framework report (Moore et al. 2005) showed that the coding for incontinence as a principal diagnosis on hospital morbidity records is inadequate. But even if it was adequate, most of the expenditure in hospital that is due to incontinence is for patients whose principal diagnosis is not incontinence.

The technique used to estimate expenditure on admitted patient hospital services considered three components of this expenditure separately: long-stay hospital patients; shorter-term patients with incontinence as an additional diagnosis to their main diagnosis; and patients whose main diagnosis was incontinence.

The National Hospital Morbidity Database (NHMD) is a compilation of electronic summary separation records from admitted-patient morbidity data collections in Australian hospitals (AIHW 2012b). Expenditure on incontinence for patients whose main diagnosis was incontinence can be directly retrieved from the NHMD, whereas estimation of expenditure for the other two groups must use other data sources as well.

For 2008–09, the NHMD recorded 7,957 patients diagnosed with incontinence who stayed in hospital for more than three months. On average, the cost of these patients' incontinence is estimated to be \$43 per day in hospitals (derived from Moore et al. 2005, inflated to 2008–09 prices). According to the 2009 SDAC, 44% of long-stay hospital patients always needed help with bladder or bowel control and 24% sometimes needed help, much the same as in 2003 (45% and 23% respectively). Therefore, the 2008–09 annual incontinence cost for these long-stay hospital patients who always or sometimes needed help with bladder/bowel control was \$51.3 million.

Expenditure for patients in hospital for less than three months who had a diagnosis of incontinence additional to their main diagnosis can be estimated in a similar way. Applying a cost of \$43 per day to their length of stay for these patients as well, the estimate of this expenditure due to incontinence was \$47.2 million. This is expected to be an underestimate because incontinence as an additional diagnosis is often not recorded in the NHMD, in circumstances when it should be.

In addition there is expenditure in hospitals for patients where the principal diagnosis is incontinence—this expenditure was \$47.0 million in 2008–09. Therefore, total hospital expenditure for incontinence in 2008–09 was estimated at \$145.5 million (Table 5.1), up from \$110.5 million in 2003 (2008–09 prices).

Medical and other health system expenditures

Medical services

Another area of expenditure on incontinence is the cost of accessing general practitioners (GPs) and specialists about incontinence.

Total expenditure for out-of-hospital medical services was estimated to be \$17.7 million in 2008–09 (Table 5.2), down from \$18.1 million in 2003 (2008–09 prices). In 2008–09, specialist attendances and unreferral GP attendances contributed \$5.6 million and \$5.1 million respectively to the total cost of out-of-hospital medical services. The remaining costs were for imaging and pathology services and for other Medicare Benefits Schedule (MBS) services such as anaesthetics, obstetrics, operations and assistance at operations and radiotherapy. It is estimated that there were around 50,000 specialist attendances and more than 92,000 unreferral GP attendances for urinary incontinence nationally in 2008–09, compared with 30,000 and 94,000 attendances in 2003 respectively.

Table 5.2: Expenditure on out-of-hospital medical services^(a) for incontinence, 2008–09

Area of expenditure	Expenditure (\$million)
Specialist and other MBS	8.0
Specialist attendances	5.6
Other MBS medical services ^(b)	2.4
Unreferred (GP) attendances	5.1
Imaging and pathology	4.0
Total out-of-hospital medical services	17.7

(a) Out-of-hospital medical services expenditure is reliant on sample survey data that can vary from year to year. Time series comparisons should be treated with caution.

(b) Includes Medicare Benefits Schedule broad type of service groups: anaesthetics, obstetrics, operations and assistance at operations and radiotherapy.

Note: The estimates contained in this section are derived using a combination of Bettering the Evaluation and Care of Health (BEACH) survey and Medical Benefits Scheme data. The BEACH data were collected by the Family Medicine Research Centre of the University of Sydney in collaboration with the AIHW. The BEACH survey data were aggregated over 3 years to estimate the proportion of GP encounters in which incontinence was a 'problem managed'. This proportion was then applied to the MBS data for the reference year. Due to the use of survey-based data in this methodology, time series comparisons of expenditure estimates should be treated with caution.

Source: AIHW Disease expenditure database.

Pharmaceuticals

About 201,000 prescription items were prescribed for incontinence in 2008–09. This comprises 2.2 pharmaceuticals per GP attendance. Total expenditure on prescription pharmaceuticals in 2008–09 was estimated to be \$3.1 million.

Most incontinence-related pharmaceuticals were for urinary incontinence, partly because this form of incontinence is more prevalent. Urologicals (60.7% of all incontinence drugs prescribed) and sex hormones (16.8%) were the most common categories, and both were exclusively for urinary incontinence. Psychoanaleptics (9.7%) were next most common, prescribed largely for urinary incontinence (92%). Only 2% of prescribed drugs for incontinence were for fecal incontinence. However, there were four and a half times more prescriptions made for constipation. Drugs for constipation are not categorised as incontinence drugs but some constipation drugs are prescribed for fecal incontinence (for examples see Schnelle et al. 2010).

Other health services

It is not yet possible to estimate expenditures in Australia for incontinence for non-admitted patient services, other health professional services or over-the-counter medicaments. It is known that people with incontinence do quite often see physiotherapists (Neumann 2008), and the use of non-admitted patient services in hospitals is considerable. However, some of the expenditure for non-admitted patient services is included in the specialist service expenditure calculated above.

The Australian Government provided \$3.8 million in 2008–09 for the National Continence Management Strategy (NCMS) (DoHA unpublished data). This expenditure funded specific projects aimed at improving the awareness, prevention and management of incontinence. This expenditure is included in 'other health services' in Table 5.1.

Continence aids

The Australian Government provided \$31.6 million in 2008–09 for the Continence Aids Assistance Scheme (CAAS) (DoHA unpublished data). This program was designed to give help to members of the community with permanent and severe incontinence. It provided financial aid for continence products such as pads and catheters to help ease the burden of incontinence on sufferers' lifestyles and allow them to maintain a level of participation in the community.

As a comparison, industry sources indicate that the wholesale expenditure for continence aids purchased from supermarkets in 2008–09 was around \$54 million (Gloria 2009). Of this, \$31.6 million was funded through the CAAS, which suggests that costs met by users would have been in the order of \$22.4 million.

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