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Incontinence in Australia

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*Authoritative information and statistics
to promote better health and wellbeing*

Incontinence in Australia

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Contents

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Abbreviations

ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Program
ACAP MDS	ACAP Minimum Data Set
ACAT	Aged Care Assessment Team
ACFI	Aged Care Funding Instrument
ADL	activities of daily living
ACFI	Aged Care Funding Instrument
AIHW	Australian Institute of Health and Welfare
AHS	Australian Health Survey
AQoL	Assessment of Quality of Life instrument
AROC	Australasian Rehabilitation Outcomes Centre
Barthel	Barthel Activities of Daily Life Index
BEACH	Bettering the Evaluation and Care of Health survey
BMI	body mass index
CALD	culturally and linguistically diverse
CAAS	Continence Aids Assistance Scheme
CACP	Community Aged Care Packages
CAPS	Continence Aids Payment Scheme
CFA	Continence Foundation of Australia
CNP	Community Nursing Program
COMS	Continence Outcomes Measurement Suite
CURF	confidentialised unit record file
DAE	Deloitte Access Economics
DALY	disability adjusted life year
DHS	Department of Human Services
DoHA	Department of Health and Ageing
DVA	Department of Veterans' Affairs

EACH	Extended Aged Care at Home packages
EACHD	Extended Aged Care at Home Dementia packages
EQ5D	European Quality of Life Measure—5D
FGM	female genital mutilation
FIM™	Functional Independence Measure
GP	general practitioner
HACC	Home and Community Care
HACC MDS	HACC Minimum Data Set
HRQoL	health-related quality of life measures
HUI3	Health Utilities Index—Version 3
ICD-10	International Classification of Diseases Tenth Revision
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
ICF	International Classification of Functioning, Disability and Health
ICIQ	International Consultation on Incontinence Questionnaire
ICPC-2 PLUS	International Classification of Primary Care, version 2—clinical coding system
ICS	International Continence Society
INI	Initial Needs Identification assessment tool
ISI	Incontinence Severity Index
KHQ	King's Health Questionnaire
LGBTI	lesbian, gay, bisexual, transgender and intersex community
LUTS	lower urinary tract symptoms
MBS	Medicare Benefits Schedule
NCHL	National Continence Helpline
NCMS	National Continence Management Strategy
NCP	National Continence Program
NHMD	National Hospitals Morbidity Database
NHS	National Health Survey
NPTM	National Public Toilet Map
ONI	Ongoing Needs Identification assessment tool

PBS	Pharmaceutical Benefits Scheme
QUID	Questionnaire for urinary incontinence diagnosis
RCS	Residential Classification Scale
RFIS	Revised Fecal Incontinence Scale
RUIS	Revised Urinary Incontinence Scale
SAHOS	South Australian Health Omnibus Survey
SAS	Stoma Appliance Scheme
SDAC	Survey of Disability, Ageing and Carers
SF36V1, SF36V2	SF®-36 Health Survey—Version 1 and 2
UDI-6	Urinary Distress Inventory 6
UI	urinary incontinence
USA	United States of America
UTIs	urinary tract infections
WHA	The Australian Longitudinal Study on Women's Health, or Women's Health Australia
WHO	World Health Organization
WHODAS 2.0	WHO Disability Assessment Tool version 2.0
Wexner FCGS	Wexner Faecal Continence Grading Scale

Symbols

—	nil or rounded to zero
. .	not applicable
n.a.	not available
n.e.c.	not elsewhere classified
n.f.d.	not further distinguished
n.p.	not publishable because of small numbers, confidentiality or other concerns about the quality of the data

Summary

Incontinence is affecting an increasing number of people. It is an uncomfortable issue, yet its serious nature warrants a better understanding of the experiences of sufferers and their carers. This report looks at the prevalence, experiences and cost of incontinence in Australia, with a focus on people with severe incontinence. It suggests a set of standard questions for collecting information to improve accuracy and comparability of data.

Who does incontinence affect?

In 2009, 316,500 people (1.5% of the Australian population) experienced severe incontinence. Of these people, 91.0% also had a severe or profound core activity limitation, indicating they had high-care needs. About 1 in every 14 people aged 65 and over (7.2%) and nearly 1 in 4 people aged 85 and over (24.5%) experienced severe incontinence, compared with 1 in 166 people aged under 65 (0.6%). The prevalence of severe incontinence was higher in females (2.0%) than males (1.0%).

Evidence is limited about the prevalence of incontinence among Aboriginal and Torres Strait Islander people, and culturally and linguistically diverse, and sex and gender diverse communities, and results are mixed. While some groups have higher risk factors for incontinence, more research is needed to know whether this translates to higher prevalence.

About 72,900 primary carers provided help with managing someone else's incontinence—4 in 5 carers were female (81.2%), and 3 in 4 spent 40 hours or more per week caring (73.0%).

How are people affected?

People with severe incontinence generally experience more severe disability and health problems than other people with disability. While this report identifies many of the problems caused by severe incontinence, it is difficult to determine the extent to which these are partly caused by accompanying limitations and health issues.

The labour force participation rate for people with severe incontinence was 26.1%, considerably lower than for people without severe incontinence (55.8%). People aged 15 and over with severe incontinence were more likely to report being in fair (34.0%) or poor (22.2%) general health than people without severe incontinence (24.8% and 10.4% respectively).

Primary carers who assist people with severe incontinence are more likely to report strained relationships with those they care for, to need more respite care, and to report lower labour force participation. This is likely due to a combination of: the effect of tasks involved in helping manage incontinence; and that over 90% of people with severe incontinence also had a severe or profound core activity limitation, indicating they had high care needs.

How much is spent on incontinence?

In 2008–09, the estimated total expenditure on incontinence was $1.6 billion, with the largest share spent on residential aged care ($1.3 billion), followed by hospitals ($145.5 million), the Stoma Appliance Scheme ($67.6 million) and the Continence Aids Payments Scheme (formerly the Continence Aids Assistance Scheme) ($31.6 million).

Section 1 Incontinence in Australia

1 Introduction

An increasing number of people in Australia are affected by incontinence, either directly experiencing it themselves, or indirectly through caring for incontinence sufferers. Section 1 of this report presents statistics on the size of the problem, the characteristics of people with incontinence and of those who care for them, and the financial costs of incontinence in Australia. Section 2 suggests a set of standard questions for collecting information on incontinence in Australia, to improve accuracy and comparability of data.

In 2006, the Australian Institute of Health and Welfare (AIHW) released *Australian incontinence data analysis and development* (AIHW 2006), which included a review of the literature and results on incontinence from the 2003 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC), and estimates of expenditure. This updated report was prompted by the release of the 2009 SDAC.

In 2012, the AIHW released a bulletin, *Incontinence in Australia: prevalence, experience and cost* (AIHW 2012a), with brief findings of the 2009 SDAC data. This report and the previous AIHW publications on incontinence were commissioned by the Department of Health and Ageing.

Australian incontinence initiatives

Since 2006, the Australian Government has supported the prevention and management of incontinence through three initiatives: the National Continence Program (NCP), the Continence Aids Payment Scheme (CAPS), which replaced the Continence Aids Assistance Scheme in 2010, and the Stoma Appliance Scheme. 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 helps people with permanent and severe incontinence meet some of the costs of their incontinence products. The Stoma Appliance Scheme provides stoma-related products free to people with stomas.

Methods and data sources

Chapter 2 considers and updates the references used in the 2006 AIHW report. In several cases follow-up work was identified, most notably further developments in classification of incontinence by the International Continence Society and new releases of bulletins and articles arising from the Australian Continence Outcome Measurement Suite Project.

The AIHW reviewed available work published since the 2006 report, in consultation with several Australian experts in incontinence research (see Acknowledgments). As a result, a selection of more than 30 articles was included in the discussion in Chapters 2 and 3.

Analysis of the 2009 SDAC was used in Chapters 4 and 5. Further information on the technical aspects of this survey is in Chapter 4. A summary of the 2009 ABS SDAC data quality declaration can be viewed at: <http://bit.ly/10fZbDb>. It should be noted that the SDAC is a sample survey and therefore sampling errors are associated with all estimates.

Several data sources were used in Chapter 6, including the Aged Care Funding Instrument, the Pharmaceutical Benefits Scheme, the Bettering the Evaluation and Care of Health project and the Stoma Appliance Scheme.

2 Definition and measurement of incontinence

Defining and classifying incontinence

Estimates of prevalence and severity of incontinence vary widely across studies. This can be partly explained by the way incontinence is identified and measured, by the variation in the populations studied, and by how incontinence is defined. Differences in definition can lead to variation in estimates of prevalence, incidence and severity.

A definition of incontinence is usually based on the presence of involuntary leakage of urine or fecal matter (Milsom et al. 2009). Several aspects of leakage are often taken into consideration: the physical symptoms of volume and frequency of leakage, and the effect on quality of life for both the sufferer and their carers.

Because there are no clear boundaries between mild incontinence and continence, attempts to define incontinence by the volume or frequency of episodes or leakage introduces arbitrary distinctions within the definition. For instance, Sansoni et al. (2006) report that many people in the community experience uncomfortable feelings of urgency without reporting episodes of incontinence.

Another way of defining incontinence is the failure or breakdown of the bodily functions of continence. The International Classification of Functioning, Disability and Health (ICF) (WHO 2001) includes a classification of Body Functions.

The ICF is a reference member of the World Health Organization Family of International Classifications, and complements the International Classification of Diseases (ICD). For more information on the ICF and its use in this report to map data on incontinence, see Chapters 7 and 9.

The ICF classifies bodily continence as:

- b6202 Urinary continence: Functions of control over urination
- b5253 Faecal continence: Functions involved in voluntary control over the elimination function.

Incontinence can therefore be defined as the failure or breakdown of either or both of these two functions.

Norton et al. (2006) suggest that the definition of incontinence should also include the social and/or hygienic elements of the problem.

The International Classification of Diseases Tenth Revision (ICD-10) includes codes for urinary incontinence (N39.3, N39.4) and fecal incontinence (R15) (WHO 2013). However, incontinence is more than simply a medical condition, as it incorporates aspects of body function, activity limitation and participation restriction. As a result, it is best approached from the functioning approach taken by the ICF.

Identifying incontinence in the SDAC

In Chapters 4 and 5, only severe incontinence as defined by the SDAC is considered. This survey is one of the best available sources of high-quality, comprehensive information about sufferers of incontinence and their carers in Australia. The questions and concepts used in the SDAC are closely aligned with the ICF. Whether or not a person has severe incontinence is determined by a person's responses to questions about:

- difficulty controlling bladder or bowel
- need for help in managing this difficulty, and whether this help is required, always or only sometimes
- whether continence aids are used.

Further information is collected in the SDAC that does not contribute to a definition but which extends understanding of incontinence to include the involvement of carers. This covers:

- whether help is required in using the toilet
- whether a member of a household assists other household members with using the toilet or with managing a bladder or bowel problem.

The SDAC does not look at volume or frequency of leakage of fluid or matter or the kind of fluid or matter (that is, urine versus fecal matter or flatus).

It should be noted that all persons identified as suffering from severe incontinence in the SDAC are considered to have a disability, and most of these have a severe or profound core activity limitation (see Box 2.1 for SDAC definitions). The SDAC defines three core activity limitations (communication, mobility and self-care) and incontinence is identified as a limitation in self-care.

Box 2.1: 2009 SDAC definitions

Disability

The 2009 SDAC asked a series of 17 questions to identify people with disability. A person had 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

(continued)

Box 2.1 (continued): 2009 SDAC definitions

- restriction in physical activities or in doing physical work
- disfigurement or deformity; in the 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 are still restricted
- any other long-term condition resulting in restriction.

Only people who were identified as having disability were then asked the following questions relating to incontinence.

Assistance with bladder/bowel control or toileting

The survey asked 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.

Assistance with toileting is a different concept to assistance with managing bladder or bowel control. For example, a person may need assistance with toileting if their physical limitation prevents them from being able to access the toilet (that is, functional incontinence).

Self-care assistance

In the 2009 SDAC, 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 specifically with managing bladder or bowel control.

Continence and toileting aids

The term 'aids and equipment' is defined in the 2009 SDAC as 'any device used by persons with 1 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.

Severe incontinence

For the purposes of this report, people with disability were identified as having severe incontinence if they:

- answered 'yes' to having difficulty with controlling bladder or bowel functions and 'yes' to ever needing help with managing this difficulty (either always or sometimes needing help)

and/or

- answered 'yes' to using continence aid(s).

Source: ABS 2010

Types of incontinence

There are two distinct types of incontinence: urinary and fecal or anal incontinence (for the distinction between fecal and anal incontinence, see 'Definition of fecal incontinence' in this chapter). Further distinctions can then be made on the basis of a number of characteristics.

While it is more common to distinguish between different kinds of urinary incontinence than fecal incontinence, the following characteristics are sometimes used for both:

- 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).

Definition of urinary incontinence

A key definition was published by the International Continence Society (ICS) in 2002 (Abrams et al. 2002:168):

> Urinary incontinence is the complaint of any involuntary leakage of urine.

The authors indicated that it should stand alongside the older definition:

> Urinary incontinence is the involuntary loss of urine that is a social or hygienic problem.

Both definitions were necessary because the first could be used as a basis for measuring prevalence of incontinence, while the second reflected sufferers who were likely to seek advice and treatment.

The authors described three key types of urinary incontinence:

- *Stress urinary incontinence* is the complaint of involuntary leakage on effort or exertion, or on sneezing or coughing.
- *Urge urinary incontinence* is the complaint of involuntary leakage accompanied by or immediately preceded by urgency.
- *Mixed urinary incontinence* is the complaint of involuntary leakage associated with urgency and also with exertion, effort, sneezing or coughing.

Hawthorne (2006) noted that the 2002 ICS urinary incontinence definition was widely accepted.

The ICS report indicated different levels of measurement were:

- symptoms, volunteered by the patient or respondent
- signs—that is, clinically observable verification of urinary leakage
- urodynamic observations—that is, outcomes of tests carried out under clinical supervision.

In the Continence Outcomes Measurement Suite report, Thomas et al. (2006:30) noted that urinary incontinence was a broad-ranging term used to describe a variety of conditions, and that 'the vast majority of research articles in the area of incontinence do not define what they specifically mean by either urinary or faecal incontinence'.

It could be argued that a definition is not necessary if there is an acceptance by the sufferer, or their carers, or by clinicians' own assessment, that incontinence is present. This reflects the significance placed on the effect that incontinence has on quality of life. Similarly, in the SDAC, people are identified as suffering from incontinence in response to questions relating to symptoms they or their carers observe, rather than asking about volume or frequency (see 'Identifying incontinence in the SDAC').

Difficulties in defining incontinence may also be due to difficulties in defining the boundary between continence and incontinence. As well, incontinence is a sensitive subject, where it is important to carefully determine how much information is required for a given study in order to avoid unnecessary embarrassment.

Definition of fecal incontinence

In 2005, the ICS released a definition for fecal incontinence closely related to its earlier definitions of urinary incontinence:

> Faecal incontinence: any involuntary loss of faecal material (Abrams et al. 2006)

Similar to urinary incontinence, Thomas et al. (2006) noted that 'very few articles addressing faecal incontinence define the term either generally or within the parameters of the research'; although they go on to indicate that this may be changing.

The 2005 ICS definition also identifies a common distinction between fecal and anal incontinence. Fecal incontinence is defined as any involuntary loss of fecal material; anal incontinence is defined as any involuntary loss of faecal material and/or flatus (flatus incontinence is defined as any involuntary loss of gas—flatus). Many studies of incontinence exclude leakage of flatus (for example, Hawthorne 2006).

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 taken into account, 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. This can be for a variety of reasons, including where the study was conducted (for example, in a clinical setting or in the community). The setting can affect the method used to collect the data, and thus the type and precision of information collected that are used to build the 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 surveys of incontinence sufferers, so definitions are based on reporting by sufferers or their carers. These usually include less precise reporting of volume and frequency, and occasionally indications of inconvenience, embarrassment or bother (Rockwood 2004, Irwin et al. 2011). Such studies are more likely to contribute to an understanding of people’s experience of incontinence, but they may be less precise or objective in identifying the quantitative severity of incontinence.

However, some questionnaires do ask the respondent for some indication of intensity or severity (Hawthorne 2006), such as the South Australian Health Outcomes Survey (SAHOS) in 2004 (Hawthorne 2006). This survey included three continence outcome measures: the Urogenital Distress Inventory 6 (UDI-6), the Incontinence Severity Index (ISI) and the Wexner Faecal Continence Grading Scale (Wexner FCGS).

Each of these asked respondents for some indication of volume or frequency. For instance, the UDI-6 includes the question, ‘Do you experience and, if so, how much are you bothered by urine leakage related to the feeling of urgency?’, to which responses can be ‘Not at all’, ‘Slightly’, ‘Moderately’ or ‘Greatly’. The key concept of severity being measured here is bothersomeness, though it is to be expected that this would be affected by volume and frequency of urine leakage (Sansoni 2006).

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

3 Prevalence estimates and risk factors – a review of the literature

Prevalence estimates vary widely in the literature due to a number of definitional and methodological factors (see Figure 3.1). Some studies limit their population to a particular high-risk group, such as older people, while others present estimates broken down by gender and age groups. In all cases, it is important to consider the definition of incontinence and study methodology when interpreting the rates.

This chapter summarises the prevalence estimates from literature from 2006 onwards (except the SAHOS, which was conducted in 2004 and reported by Hawthorne in 2006; for information on studies before 2006, see *Australian incontinence data analysis and development* (AIHW 2006).

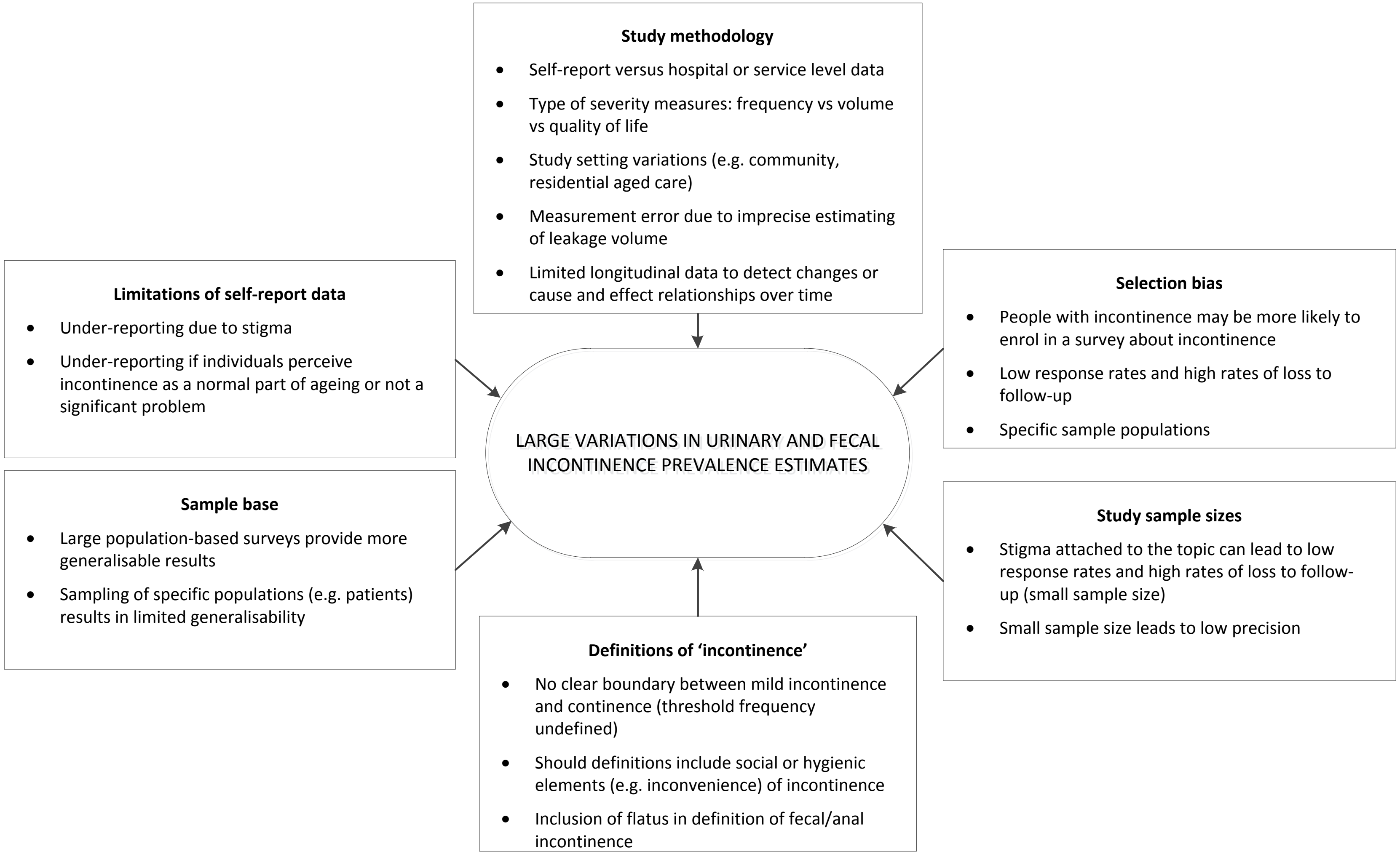
Additional Australian prevalence estimates are in Chapter 4. These are based on analysis of the 2009 SDAC.

International prevalence estimates (people living in the community)

Urinary incontinence

Table 3.1 presents prevalence estimates from large systematic reviews; the largest population-based survey conducted to date that included participants from Canada, Germany, Italy, Sweden and the United Kingdom; and additional recently published analytical studies. The current 2002 ICS definition of 'the complaint of any involuntary leakage of urine' (Abrams et al. 2002) was referred to consistently across the reports and is often used as a guideline for inclusion and exclusion criteria.

In 2007, a systematic review and meta-analysis described the prevalence and risk factors for urinary and fecal incontinence in adults in long-term residential care and people living in the community (the community-living population), and the effectiveness of diagnostic methods and clinical interventions for incontinence (Shamliyan et al. 2007). The ICS definitions of urinary (stress, urge, mixed), anal (flatus and fecal) and combined incontinence were used to guide the review, and identified 1,077 articles between 1990 and 2007 that matched inclusion criteria (see Chapter 2 for more detailed definitions). The review presents pooled prevalence estimates for urinary, anal and fecal incontinence.



Study methodology

- Self-report versus hospital or service level data
- Type of severity measures: frequency vs volume vs quality of life
- Study setting variations (e.g. community, residential aged care)
- Measurement error due to imprecise estimating of leakage volume
- Limited longitudinal data to detect changes or cause and effect relationships over time

Limitations of self-report data

- Under-reporting due to stigma
- Under-reporting if individuals perceive incontinence as a normal part of ageing or not a significant problem

Selection bias

- People with incontinence may be more likely to enrol in a survey about incontinence
- Low response rates and high rates of loss to follow-up
- Specific sample populations

LARGE VARIATIONS IN URINARY AND FECAL INCONTINENCE PREVALENCE ESTIMATES

Sample base

- Large population-based surveys provide more generalisable results
- Sampling of specific populations (e.g. patients) results in limited generalisability

Study sample sizes

- Stigma attached to the topic can lead to low response rates and high rates of loss to follow-up (small sample size)
- Small sample size leads to low precision

Definitions of 'incontinence'

- No clear boundary between mild incontinence and continence (threshold frequency undefined)
- Should definitions include social or hygienic elements (e.g. inconvenience) of incontinence
- Inclusion of flatus in definition of fecal/anal incontinence

Source: AIHW; Milsom et al. 2009.

Figure 3.1: Reasons for variations in prevalence estimates

Table 3.1: Selection of international urinary incontinence prevalence estimates among the community-living population since 2006 (%)

Source	Definition	Age (years)	Males	Females	Persons
Systematic reviews, reviews and meta-analyses					
Irwin et al. (2011)	Current ICS (2002) – 'any UI'	20 and over	n.p.	n.p.	8.2
Buckley and Lapitan (2010)(a)	Current ICS (2002) – 'any UI'	20–39	2.0–2.4	7–37	n.p.
		40–59	2–19	31–48	n.p.
		60–79	3–23	30–61	n.p.
		80 and over	8–22	37–63	n.p.
Shamliyan et al. (2007)	Current ICS (2002) 'ever' had UI	19–44	4.8	21.0	n.p.
		45–64	11.2	34.0	n.p.
		>65	21.1	39.0	n.p.
Irwin et al. (2006)	Current ICS (2002) – 'any UI'	under 40	2.4	7.3	n.p.
		40–59	5.2	13.7	n.p.
		60 and over	10.4	19.3	n.p.
		All ages	5.4	13.1	n.p.
More recent analytical studies					
Markland et al. (2011) USA	Urine leakage during physical or non-physical activity and before reaching the toilet	Age-standardised rate	13.9	51.1	n.p.
Lasserre et al. (2009) France	Current ICS (2002) definition	29 and younger	n.p.	5.3	n.p.
		30–39	n.p.	16.5	n.p.
		40–49	n.p.	21.9	n.p.
		50–59	n.p.	30.4	n.p.
		60–69	n.p.	34.5	n.p.
		70–79	n.p.	34.0	n.p.
		80+	n.p.	46.6	n.p.
Nygaard et al. (2008)(b) USA	At least weekly leakage or monthly leakage of volumes more than a few drops	20–39	n.p.	6.9	n.p.
		40–59	n.p.	17.2	n.p.
		60–79	n.p.	23.3	n.p.
		80+	n.p.	31.7	n.p.
		20 and over	n.p.	15.7	n.p.

* UI denotes urinary incontinence.

(a) This study presented ranges of urinary incontinence prevalence for each age and sex group.

(b) Weighted prevalence rates in non-pregnant US women.

Irwin et al. (2011) reported worldwide prevalence rates for people aged 20 and over—using gender and age-stratified prevalence data from Irwin et al. (2006) and gender and age-stratified worldwide and regional population estimates from the United States Census Bureau International Data Base. The 2006 study was the largest population-based survey available at the time to estimate prevalence rates of incontinence and other lower urinary tract symptoms in five countries. Estimates in Irwin et al. (2011) assume that prevalence data from the 2006 study are not, on average, different from regional and worldwide prevalence rates.

A review of the best available evidence was presented by Buckley and Lapitan (2010) at the Fourth International Consultation on Incontinence presenting 'any' urinary incontinence. All prevalence estimates presented from this study exclude outliers, except for females aged 20–39.

Authors of the reviews acknowledge the continuing difficulties of identifying a concise prevalence estimate of urinary incontinence given the varying definitions and methods of measurement. For instance, Shamliyan et al. (2007) came across 20 different definitions for 'urinary incontinence' within the included studies and said that this variation contributed substantially to the prevalence estimates.

Table 3.2: Selection of international fecal incontinence prevalence estimates among community-living population since 2006 (%)

Source	Definition	Age (years)	Males	Females	Persons
		Systematic reviews and meta-analyses			
Pretlove et al. (2006) Meta-analysis using random effects model	Fecal incontinence	Younger than 60	0.8	1.6	1.3
		60 and over	5.1	6.2	6.2
		All ages	3.5	4.5	n.p.
Shamliyan et al. (2007) Pooled prevalence estimates using random effects model	Fecal incontinence	45–64	6.4	7.3	n.p.
		65 and over	7.2	8.5	n.p.
		80 and over	9.6	9.5	n.p.
		Analytical studies			
Alsheik et al. (2012) USA	Fecal incontinence or 'leakage' or 'soiling'	Gastroenterologist patient population	3.2.	8.6.	11.6
Kang et al. (2012) South Korea	Events of recurrent uncontrolled passage of fecal material at least once in the past 3 months	Health promotion clinic			
		20–30	n.p.	n.p.	3.6
		31–40	n.p.	n.p.	3.2
		41–50	n.p.	n.p.	6.3
		51–60	n.p.	n.p.	9.8
		61–70	n.p.	n.p.	12.2
		71+	n.p.	n.p.	11.8
		All ages	n.p.	n.p.	6.4
Rømmen et al. (2012) Norway	Fecal incontinence: involuntary leakage if any stool weekly or more often during the last month	30–39	n.p.	1.7	n.p.
		40–49	n.p.	1.5	n.p.
		50–59	n.p.	2.2	n.p.
		60–69	n.p.	3.8	n.p.
		70–79	n.p.	5.4	n.p.
		80+	n.p.	7.5	n.p.
		All ages	n.p.	3.0	n.p.

(continued)

Table 3.2 (continued): Selection of international fecal incontinence prevalence estimates among community-living population since 2006 (%)

Source	Definition	Age (years)	Males	Females	Persons
		Analytical studies			
Malmstrom et al. (2010) (USA)	Any loss of control of bowel or stool in past 12 months	African-Americans 52–68	3.4	6.1	5.0
Parés et al. (2010) Spain	Involuntary leakage of flatus, liquid or solid stool at least once in the past 4 weeks	Patients aged >18 who attended one of 10 health-care centres	8.6	12.0	10.8
Whitehead et al. (2009) USA	Involuntary leakage of solid, liquid or mucus during the last 30 days	20 and over	7.7	8.9	8.3
Nygaard et al. (2008)[(a)] USA	At least monthly leakage of solid, liquid or mucus	20–39	n.p.	2.9	n.p.
		40–59	n.p.	9.9	n.p.
		60–79	n.p.	14.4	n.p.
		80+	n.p.	21.6	n.p.
		All ages	n.p.	9.0	n.p.

(a) Weighted prevalence rates in non-pregnant women in the United States.

As reported in *Australian incontinence data analysis and development* (AIHW 2006), there were noticeable sex and age trends. Older people (particularly those aged 60 and over) and females consistently reported higher rates of urinary incontinence than younger people and males (Buckley & Lapitan 2010; Markland et al. 2011; Shamliyan et al. 2007).

Stress incontinence was the most prevalent type of urinary incontinence reported by women aged 19–44 (12.8%) and 45–64 (21.5%). Mixed urinary incontinence was most prevalent in women older than 65 (16.8%). The prevalence of urge incontinence gradually increased as age increased—from 5% in younger women to 10% in women aged 45–64, up to 12% in women aged 65 and over (Shamliyan et al. 2007). In comparison, urge incontinence dominated for males, with the prevalence increasing from 3.1% in those aged 19–44 to 11.7% in those aged 65 and over.

Fecal incontinence

Fecal incontinence rates exclude the leakage of flatus, while anal incontinence rates include flatus leakage. Most studies report on fecal incontinence; however, some report a prevalence estimate of anal incontinence. For the purpose of this report, most estimates will relate to fecal incontinence, unless otherwise specified, because it is difficult to measure the leakage of flatus.

Two systematic reviews have been published since 2006 reporting combined prevalence rates of fecal and anal incontinence (see Table 3.2). Overall prevalence rates ranged from 0.8% in younger males and 1.6% in younger females to 9.6% in males and 9.5% in females aged over 80. Both reviews demonstrate an increasing prevalence of fecal and anal incontinence with increasing age. A gender effect was not evident; although fecal incontinence was more common in females than males, this difference was not statistically significant.

When interpreting these results, it is important to note that the authors of both reviews comment on the lack of consistency in definitions across the included studies. The more recent analytical studies tend to focus on specific population groups and report prevalence rates using different time frames and wording to define incontinence. These differences can account for the variation in estimates, as they do for urinary incontinence. Also, the sensitive nature of the topic can lead to an underestimation of the true prevalence, as only a small proportion of people with the condition may seek help or report the issue in a survey.

Table 3.3: Selection of Australian prevalence estimates for urinary incontinence among the community-living population (%)

Source	Definition	Age (years)	Males	Females	Persons
Sims et al. (2011)	Participants asked, Have you ever had difficulty holding your urine until you get to the toilet? (Urge)				
	Often	65–74	3.0	8.1	n.p.
		75+	8.7	3.5	n.p.
	Occasionally	65–74	18.1	23.3	n.p.
		75+	16.3	30.6	n.p.
	Do you ever leak urine when you cough, sneeze or laugh? (Stress)	65–74	6.8	34.6	n.p.
		75+	7.7	28.5	n.p.
Kwong et al. (2010)	International Consultation on Incontinence Questionnaire (ICIQ)				
	Leakage twice per week in the past 4 weeks	70–74	12.0	n.p.	n.p.
		75–79	14.7	n.p.	n.p.
		80–84	15.6	n.p.	n.p.
		85–89	26.3	n.p.	n.p.
		90+	16.3	n.p.	n.p.
		All ages	14.8	n.p.	n.p.
Botlero et al. (2009)	Questionnaire for Urinary Incontinence Diagnosis (QUID)				
	Stress—leakage when coughing, sneezing, bending down, lifting something, walking quickly, jogging or exercising?	<35	n.p.	16.7	n.p.
		35–44	n.p.	25.3	n.p.
		45–54	n.p.	17.5	n.p.
		55–64	n.p.	14.7	n.p.
		65–74	n.p.	11.7	n.p.
		75+	n.p.	12.1	n.p.
		All ages	n.p.	16.1	n.p.

(continued)

Table 3.3 (continued): Selection of Australian prevalence estimates for urinary incontinence among the community-living population (%)

Source	Definition	Age (years)	Males	Females	Persons
Botlero et al. (2009)	Urge—urine leakage while undressing to use the toilet, a strong need to urinate and leak prior to reaching the toilet or need to rush to the bathroom because of a sudden need to urinate?	<35	n.p.	0.0	n.p.
		35–44	n.p.	5.3	n.p.
		45–54	n.p.	4.4	n.p.
		55–64	n.p.	5.1	n.p.
		65–74	n.p.	10.9	n.p.
		75+	n.p.	24.2	n.p.
		All ages	n.p.	7.5	n.p.
	Mixed—combined stress and urge	<35	n.p.	11.1	n.p.
		35–44	n.p.	12.0	n.p.
		45–54	n.p.	18.4	n.p.
		55–64	n.p.	20.6	n.p.
		65–74	n.p.	19.5	n.p.
		75 +	n.p.	18.2	n.p.
		All ages	n.p.	18.1	n.p.
Botlero et al. (2008)	Definitions of UI varied between studies	Varying	n.p.	12.8–46.0	n.p.
Hawthorne (2006) (SAHOS 2004)	Incontinence Severity Index (ISI) — assesses frequency and amount of leakage	15–19	2.0	11.0	6.0
		20–29	5.0	18.0	11.0
		30–39	4.0	40.0	22.0
		40–49	6.0	44.0	25.0
		50–59	17.0	55.0	36.0
		60–69	13.0	48.0	31.0
		70–79	26.0	40.0	34.0
		80+	30.0	41.0	37.0
		All ages	10.0	38.0	24.0

Australian prevalence estimates (people living in the community)

Urinary incontinence

Table 3.3 presents estimates from recent Australian-based reviews and studies that consider urinary incontinence in the community-living population. The large variation between studies in Australian prevalence estimates is similar to that of international estimates.

The 2004 SAHOS study, and incontinence data published by Hawthorne in 2006, uses the ISI and the UDI-6 to assess for urinary incontinence. These measures are based on the ICS definition of incontinence. For the purposes of this report, only the ISI-based estimates are reported, as this measure was considered to have superior psychometric properties over the UDI-6 (Hawthorne 2006). The ISI comprises two items: how often do you experience urine leakage and how much urine do you lose? A score is given that combines responses to both questions. Estimates for males ranged from 2.0% for those aged 15–19 to 30% for those aged 80 and over. Female estimates increased steadily from 11% for those aged 15–19 to 55% in those aged 50–59, then decreased to 48% for females aged 60–69 and steadied at about 40% for those aged 70 and over.

More recently, Botlero et al. (2008) reviewed the literature since 1980 regarding the prevalence and incidence of urinary incontinence in Australian women and found that prevalence estimates ranged from 12.8 to 46.0%. They commented that differences between studies were due to varying response rates, the inclusion of women in institutional care, the method of data collection, the different questions used to identify different types of urinary incontinence, the period over which the incontinence occurred and the difference in severity.

Following the review, Botlero et al. (2009) published age-specific prevalence rates for different types of urinary incontinence (UI) in women aged 24–80 using the validated Questionnaire for Urinary Incontinence Diagnosis (QUID). This tool assesses urinary incontinence by asking, in the last 30 days: do you leak urine (even small drops), wet yourself, or wet your pads or undergarments when you cough, sneeze, bend down, lift something, walk quickly, jog or exercise (stress UI) or while undressing to use the toilet, before reaching the toilet or getting sudden, strong need to urinate (urge UI) or combination of both (mixed UI)? This study found that younger women were more likely to experience stress incontinence, whereas older women were more likely to experience urge or mixed urinary incontinence; that is:

- stress incontinence peaked at 25.3% for females aged 35–44
- urge incontinence peaked at 24.2% for females aged 75 and over
- mixed incontinence peaked at 20.6% for females aged 55–64.

Possibly due to concerns about the ageing population, more recent studies report prevalence estimates of the older community-living population and demonstrate a clear positive association for both males and females between incontinence and age (Kwong et al. 2010; Sims et al. 2011). The study by Kwong et al. (2010) used the International Consultation on Incontinence Questionnaire (ICIQ), comprising three scored items to measure the frequency, volume and quality of life effect of urinary incontinence and an unscored item to assess the cause of urinary incontinence. The prevalence rate for males increased steadily between the ages of 70 and 84 (from 12.0% to 15.6%), then rose sharply to 26.3% for men aged 85–89, before dropping to 16.3% for men aged 90 and over. These fluctuations in the much older age groups may reflect the small sample sizes—133 men aged 85–89 and 43 men aged 90 and over.

Fecal incontinence

There is limited research since 2006 reporting the prevalence of fecal or anal incontinence in the Australian community-living population.

The Hawthorne (2006) report includes both fecal and anal incontinence rates. The Wexner Faecal Continence Grading scale was used to measure the prevalence of anal incontinence. It was modified to comply with the ICS definition of fecal incontinence, by excluding the leakage of flatus (see Table 3.4).

Table 3.4: Australian prevalence estimates of faecal incontinence among the community-living population (%)

Source	Definition	Age (years)	Males	Females	Persons
Hawthorne (2006) (SAHOS 2004)	Modified Wexner Faecal Continence Grading Scale —excludes flatus to match the ICS definition of incontinence of self-report involuntary loss of liquid or solid stool that is a social or hygienic problem	15–19	2.0	6.0	4.0
		20–29	5.0	4.0	4.0
		30–39	6.0	8.0	7.0
		40–49	2.0	8.0	5.0
		50–59	7.0	14.0	11.0
		60–69	8.0	11.0	9.0
		70–79	15.0	17.0	16.0
		80+	9.0	17.0	15.0
		All ages	6.0	10.0	8.0
	Standard Wexner Faecal Continence Grading Scale —includes flatus	15–19	22.0	13.0	17.0
		20–29	23.0	23.0	23.0
		30–39	22.0	40.0	31.0
		40–49	34.0	39.0	36.0
		50–59	43.0	50.0	47.0
		60–69	43.0	45.0	44.0
		70–79	38.0	45.0	42.0
		80+	30.0	39.0	35.0
		All ages	32.0	38.0	35.0

Prevalence estimates for anal incontinence are substantially higher than fecal incontinence rates for all age groups. This reflects the broader definition of anal incontinence, including a proportion of people who may not report leakage of solid or liquid stool, but do report leakage of flatus. In nearly all age groups (except 20–29) females were more likely to experience fecal incontinence than males. A similar trend was found for anal incontinence.

Prevalence estimates from residential aged care populations

Urinary and fecal incontinence

Studies reporting incontinence estimates in residential aged care populations are less common than those for people living in the community, though the prevalence in this population is higher. Table 3.5 presents data from systematic reviews and a recent survey in Turkey that is not included in the reviews. As with the community-living population, prevalence estimates vary due to differing definitions and measurements used in the studies. The effect of the timing of the survey is unique to the measurement of prevalence in residential aged care—rates at admission differ to rates post-admission.

Table 3.5: Range of international prevalence estimates for urinary and fecal incontinence among people living in long-term care or residential aged care setting (%)

Source	Definition	Age (years)	Males	Females	Persons
Urinary incontinence					
Aslan et al. (2009) Turkey Cross-sectional study	Any involuntary loss of urine independent of the volume at least monthly	60+	20.9	43.4	n.p.
Shamliyan et al. (2007)[(a)] Systematic review	Varying definitions (e.g. any daytime incontinence, at least two episodes in past two weeks, medical record or staff report)	65+	23–72	60–78	30–77
Buckley and Lapitan (2010) Review	ICS symptom definition (2002)	Women in long-term care	n.p.	50–80	n.p.
Fecal incontinence					
Aslan et al. (2009) Turkey	Involuntary loss of solid or liquid faeces or flatus causing a social or hygienic problem	60+	6.0	14.0	n.p.
Shamliyan et al. (2007)[(a)]	Fecal incontinence with or without urinary incontinence	Adults	n.p.	n.p.	<5–12
	Combined urinary and fecal incontinence	Adults	n.p.	n.p.	4–44

(a) This systematic review and meta-analysis presents pooled prevalence estimates. Statistical heterogeneity was found between the included studies and therefore a random effects meta-analysis model was used to combine the data. Data for long-term care settings comes from studies published between 1991 and 2007 from the United Kingdom, United States, Canada, Italy and Australia.

The prevalence of urinary and fecal incontinence within residential aged care settings is considerably higher than in community settings (see Box 3.1 for incidence of incontinence). Many factors contribute to this:

- Incontinence is positively associated with ageing; hence, more people in residential aged care will experience incontinence.
- Pearson et al. (2002a) found that the top three critical factors identified by respondents contributing to the decision to move from community-based care to residential care were dementia/cognitive function, mobility and incontinence.
- Incontinence is a significant factor in decisions regarding admission to aged care homes, particularly high-care facilities—87% of Aged Care Assessment Team (ACAT) respondents identified incontinence as a significant or very significant factor when considering placement within a residential aged care facility (Pearson et al. 2002a).

Residents with cognitive impairments, physical dependency, prolonged institutionalisation, diabetes or fecal incontinence reported higher prevalence rates of urinary incontinence. The odds of fecal incontinence were increased for residents who depended on support for daily activities or eating and had increased length of stay in nursing homes from 2 weeks to 1 year (Shamliyan et al. 2007). Urinary incontinence has also been found to be a predictor of falls (Hanley et al. 2011; Wilson et al. 2011).

Box 3.1 Incidence of incontinence

The term 'incidence' refers to the number of new cases of an illness or disease, during a given period in a specified population. This is different to the term 'prevalence', which refers to the total number of individuals who have an illness or disease at a particular time divided by the population at risk of having the illness or disease at that time (Porta 2008).

Community-living population

Shamliyan et al. (2007) reported a urinary incontinence annual incidence rate of 6.3% for women of all ages when combining the results from 18 studies. The highest incidence rates were for women aged 65 and over (7.7%) and 80 and over (8.5%). In Australia, Byles et al. (2009) reported a 14.6% incidence rate in women aged 70–75 over 9 years. Studies investigating incidence of urinary incontinence in men are sparse. Current research has reported an overall annual incidence rate of 4%, which is increasing with age (Landefeld et al. 2008).

Fewer studies investigate fecal incontinence incidence rates. One recent study reported a 4-year incidence rate of 18% for women and 16% for men aged 65 and over in the United States (Markland et al. 2010). Two-thirds of the people who had developed fecal incontinence in this period reported less than one episode per month.

Residential aged care population

Few studies investigate incontinence incidence rates in residential aged care. Current available evidence suggests that urinary incontinence incidence rates are considerably higher in residential aged care settings than the community, with estimates of 27% 2 months after admission and 19% after 1 year (Shamliyan et al. 2007).

Currently, data on the differences in incidence between males and females, as well as fecal incontinence incidence rates, are limited and further research is required.

Specific population groups

Aboriginal and Torres Strait Islander people

Incontinence is a sensitive issue for both Indigenous and non-Indigenous people. However, the Indigenous community faces additional cultural, and sometimes logistical, barriers in obtaining health information and services. For example, body issues are often unspoken of in the Indigenous community due to shame and shyness (Pearson et al. 2002b). Distance to health services and language barriers can also limit access to incontinence-related health-care services for Indigenous people in rural areas.

Few studies report on the prevalence of incontinence in the Aboriginal and Torres Strait Islander population. Benness and Manning (1999; cited in Millard et al. 2001) reported an overall urinary incontinence prevalence of 54% in a sample of 281 community-dwelling, non-urban Indigenous women. Half of the women (49%) experienced stress incontinence. LoGiudice et al. (2010) reported a much lower rate of incontinence in their sample of 363 Indigenous Australians aged over 45 (9%)—however, the authors suggest that this is an underestimate of the true value because the methods used to determine incontinence had not been tested for the Indigenous population concerned.

At the Fifth National Continence Foundation of Australia Conference, Chiarelli and Brown (1997; cited in Millard et al. 2001) reported a significantly higher prevalence rate for Indigenous women aged 19–22 than non-Indigenous women of the same age. It is thought that this difference may be due to the higher fertility rate among young Indigenous women than among young non-Indigenous women. There was no significant difference for other age groups.

The Indigenous population experience many chronic conditions at a higher rate than the non-Indigenous population, including conditions that are risk factors for incontinence (see 'Associated risk factors' in this chapter). Diabetes is 3 times as common in Indigenous people than non-Indigenous people (AIHW 2012b). Being overweight is more common in non-Indigenous people (35.5%) than Indigenous people (30.5%), but obesity is almost twice as common in Indigenous people (33.6%) than non-Indigenous people (17.9%) (AIHW 2011). Dementia is more common in the Indigenous population than the non-Indigenous population, with one study citing a prevalence of 12.4% in Indigenous people aged 45 and older living in Western Australia—5 times greater than in the non-Indigenous population (Smith et al. 2008). These conditions are all risk factors for incontinence. Despite limited research regarding the Indigenous population and incontinence, the higher rates of risk factors in this population supports the idea that they may also experience a higher rate of incontinence.

Further research regarding incontinence in the Indigenous population, particularly in men and distinguishing between those living in rural, remote and very remote regions and those living in urban regions, would help identify support needs of this population. The Australian Government has developed specific educational material for the Indigenous population regarding incontinence (see <http://bit.ly/13Fpd1J>).

Culturally and linguistically diverse people

The prevalence and experience of incontinence in people from different cultural and linguistic backgrounds can differ depending on their cultural practices, English-language abilities and health literacy skills. For example, in people aged 60 and older in the United States, the prevalence of urinary incontinence was higher in non-Hispanic white women in America (41%) than non-Hispanic black (20%) or Mexican-American women (36%), while non-Hispanic black men had the highest prevalence of incontinence (21%) compared with non-Hispanic white (16%) and Mexican-American men (14%) (Anger et al. 2006a; Anger et al. 2006b). An equivalent study comparing the prevalence of incontinence in people from different cultural backgrounds has not been conducted in Australia (see Box 3.2).

In 2012, the CFA started an incontinence education and awareness project targeting culturally and linguistically diverse (CALD) communities. The project aims to develop effective engagement with CALD communities to improve their awareness of incontinence and encourage help-seeking behaviours.

Box 3.2 Cultural considerations and incontinence in Australia

Australia is a multicultural society. In 2011–12, 185,000 migrants arrived in the country, mostly from India, China and the United Kingdom (DIAC 2012a). Between 2006–07 and 2010–11, almost 51,000 people were granted offshore humanitarian visas. About 21,000 visas were for people born in south-east, southern and central Asia; 16,500 were for people born in North Africa and the Middle East; and 12,600 were for people born in sub-Saharan Africa (DIAC 2012b). People from these various cultural backgrounds may have quite different perceptions and experiences of incontinence to the general Australian population. Specific cultural incontinence-related issues include:

- Obstetric fistulas: an obstetric fistula is a hole that develops between the rectum and vagina or the bladder and vagina after a severe, prolonged, or failed childbirth. This often leads to constant incontinence, shame, social segregation and health problems, unless treated. Women giving birth in developing countries where adequate medical care is not available more frequently experience obstetric fistula than in Australia. It is estimated that 2 million young women are living with untreated obstetric fistulas in Asia and sub-Saharan Africa, and that between 50,000 to 100,000 women develop an obstetric fistula each year (WHO 2010a). In developed countries such as Australia, obstetric fistulas are rare, but can arise from malignant disease, radiation therapy or surgical injury (Wall 2006).
- Female genital mutilation (FGM): FGM is a procedure that involves partial or total removal of the external female genitalia, or other alteration to the female genitals for non-medical purposes. It is estimated that 3 million girls are at risk of FGM in Africa each year (WHO 2012). FGM is illegal in Australia, and therefore it is difficult to know the number of girls who undergo the procedure (due to a lack of reporting); however, there is anecdotal evidence that it occurs in Australia (Mathews 2011) and that children are sometimes taken overseas for family celebrations and to have FGM performed (Moeed & Grover 2012). FGM increases the risk of recurrent bladder and urinary tract infections (UTIs), cysts, infertility, and childbirth complications and deaths (WHO 2012). Urinary incontinence has been reported by medical practitioners in Australia as a complication or health risk related to FGM or cutting (Moeed & Grover 2012).

Sex and gender diverse population

Health needs and access to health-care services for people who identify as lesbian, gay or bisexual and those who are transgender or intersex (LGBTI) are unique. There is strong evidence that some groups within the LGBTI community experience specific risk factors and health conditions at higher rates than the general population. Research suggests that the LGBTI community accesses health-care services and treatment at a lesser rate to the general community—to avoid possible discrimination or in the belief that they may receive reduced quality of care (Heck et al. 2006; Mayer et al. 2008). However, recent evidence suggests that access to health-care services may be changing for some groups (Leonard et al. 2012).

In Australia, the second national survey on the health and wellbeing of gay, lesbian, bisexual and transgender Australians, completed in 2012, reported that study participants were more comfortable in accessing a range of health services than previous research suggested (Leonard et al. 2012). For instance, lesbians reported accessing health services more regularly than heterosexual females—but they also reported greater dissatisfaction with health-care services.

Despite these findings, the LGBTI community continues to harbour concerns about discrimination and a lack of knowledge within the health community regarding their particular health needs. More than 1 in 3 LGBTI participants (33.6%) in the national survey reported that they occasionally or usually hid their sexuality or gender identity when accessing services (Leonard et al. 2012).

Currently, available research regarding the LGBTI population and incontinence is scarce, with many studies being limited by their small sample size. There are specific groups within the LGBTI population who may be at increased risk of incontinence and who have been the focus of some research, particularly gay or bisexual men and people who have been through gender reassignment surgery. Research regarding lesbians and incontinence is particularly limited.

Gay or bisexual men have been the focus of a number of studies that mention incontinence, with a focus on two primary risk factors. Firstly, limited research has investigated the health outcomes of gay or bisexual men who participate in anal sexual intercourse. Evidence remains mixed as to whether anal sphincter injury or incontinence can be caused by anal sexual intercourse in men (Chun et al. 1997; Miles et al. 1993). Secondly, there has been a focus on gay or bisexual men with HIV/AIDS, because one health outcome of HIV/AIDS is diarrhoea—often experienced as fecal incontinence (Siegel et al. 2010). For gay or bisexual men with HIV/AIDS, fecal incontinence is of concern for two reasons: many worry about its wasting effect, along with the greater fear that it is signalling the progression to end-stage disease.

The nature of gender reassignment surgery may increase the incidence of incontinence in people who are transgender after surgical transition (Williamson 2010). Small studies have indicated that after reassignment surgery:

- 50% of female-to-male patients reported urinary incontinence, ranging from post-voiding dribbling to continuous incontinence (Hoebeke et al. 2005)
- 19% of male-to-female patients reported urinary incontinence (Hoebeke et al. 2005)
- 47% of transgender people reported voiding difficulties including urgency (25%), urge incontinence (17%) and stress incontinence (23%) (Kuhn et al. 2011).

Incontinence-related information on people who are born intersex (people with characteristics that do not allow for distinct identification as male or female) is limited and there is scarce information regarding the risk of incontinence post-gender assignment surgery. However, people who are intersex or who have been through gender assignment surgery may have specific health-care needs, particularly in relation to lower urinary tract function (Celayir et al. 2000).

Associated risk factors

Since 2006, research has advanced our understanding of risk factors on the development of incontinence. However, limitations in our understanding continue because:

- most studies are cross-sectional in design, allowing for the identification of associations only, not causality
- there may be confounding factors. For example, when investigating the association between obesity and incontinence, where age-standardisation is not used, the age of participants may skew the results, leading to inaccurate conclusions

- there is limited understanding of the mechanisms for many associations with incontinence.

One recent suggestion to improve the organisation of risk factors for incontinence is to use a unified classification system, identifying predictors based on the basic processes in the body that cause incontinence (Landefeld et al. 2008). This system includes five categories: physical status (for example, age, sex, obesity), genetic factors (for example, family history), neuropsychiatric conditions (for example, multiple sclerosis, dementia, depression, stroke, diabetic neuropathy), trauma (for example, childbirth, prostatectomy), and associated conditions (for example, diarrhoea, inflammatory bowel disease, menopause, smoking, constipation, urinary tract infections). These categories are limited and include overlaps, with some risk factors falling in two categories.

Age

Incontinence is not an inevitable part of ageing. However, as reported in *Australian incontinence data: analysis and development* (AIHW 2006), age is the most commonly cited factor associated with incontinence.

It is thought that changes in the pelvic structures that occur with age and increasing medical problems associated with ageing can disrupt the mechanisms of continence and may contribute to incontinence (Staskin 1986; cited in Milsom et al. 2009). For instance, in females, a decrease in estrogen levels results in deterioration of the urethra and vagina, leading to decreased urethral pressure and increased likelihood of stress and urge incontinence. In men, ageing increases the risk of enlargement of the prostate, which can lead to urgency, straining and frequency of need to urinate. Additionally, drugs to treat other illnesses experienced by older people, such as heart disease and hypertension (diuretics and alpha-blockers), can result in increased stress or urge urinary incontinence (Wilkinson 2009).

Sex

The prevalence rates of urinary incontinence are consistently reported to be higher in females than males, by a ratio of 2:1 (Milsom et al. 2009). For example, females aged 65 and older reported higher prevalence of urinary incontinence (39.0%) than males in the same age group (21.1%). In some instances, this ratio is even greater, with females aged 19–44 reporting a prevalence estimate of 21.0%, compared with 4.8% for males of the same age (Shamliyan et al. 2007).

Fecal incontinence prevalence rates do not clearly differ between women and men. Many analytical studies report higher prevalence rates in females than males; however, these differences are not significant (see Tables 3.2 and 3.4). For instance, the meta-analysis by Pretlove et al. (2006), combining data from 29 studies, found that females had slightly higher prevalence rates than males, but again, this difference was not significant.

Other risk factors

Pregnancy and childbirth

During pregnancy, many women will report stress urinary incontinence. Usually this will resolve itself after the delivery, but can be a risk factor for urinary incontinence in the immediate post-partum period and in subsequent years (Milsom et al. 2009). Possible reasons include physiological changes during pregnancy that may cause the development of incontinence later in life, or temporary physiological changes during pregnancy that may lead to incontinence in women who are pre-disposed to incontinence later in life. However, evidence to support these reasons is limited (Milsom et al. 2009).

The number of times a woman has given birth is associated with urinary incontinence later in life in most studies, with stress urinary incontinence the most commonly reported type (Milsom et al. 2009; Shamliyan et al. 2007). It is less clear if there is a threshold effect—some studies have found little or no additional risk with increasing number of births after one delivery; others report increasing risk as the number of births increase.

The effect of giving birth on continence can be investigated by comparing the prevalence of incontinence in women who deliver vaginally with the prevalence in women who deliver by Caesarean section. Vaginal deliveries tend to be a risk factor for urinary incontinence, particularly stress urinary incontinence. Mode of delivery does not appear to be a factor in the development of fecal incontinence, with research finding it occurs as often as after Caesarean section delivery and vaginal delivery (Milsom et al. 2009).

Prostate problems (including prostate cancer)

Men with prostate disease are 6 times as likely to develop incontinence than men without prostate disease, and men with prostate cancer are twice as likely to develop incontinence as men without prostate cancer (Shamliyan et al. 2009).

Prostate surgery has also been associated with incontinence. A history of any prostate surgery doubled the chance of urinary incontinence compared with no prostate surgery, and radical prostatectomy (the surgical removal of the whole prostate gland) was associated with a fourfold increased chance of urinary incontinence compared with men who had not had a radical prostatectomy (Shamliyan et al. 2009). The prevalence rates of urinary incontinence after a radical prostatectomy ranged between 2% and 57% (Milsom et al. 2009). This large variation may be due to different study methodologies or different surgical procedures.

Hysterectomy

There is conflicting evidence regarding the association between hysterectomy and incontinence. The challenge when studying this association is the confounding effect that age has on the relationship—many studies have not controlled for this effect.

Brown et al. (2000) conducted a systematic review and considered the effect of age on the relationship between hysterectomy and incontinence. They concluded that women aged 60 and over who had undergone a hysterectomy had a greater prevalence of urinary incontinence than women who had not undergone a hysterectomy. However, this was not seen in younger women.

Australian studies have found a weak association between hysterectomy and incontinence in women aged 70–75 (Byles et al. 2009) and an association between hysterectomy and urge and mixed incontinence in community-living women aged 24–80 (Botlero et al. 2009).

Urinary tract infections and lower urinary tract symptoms

There is an association between urinary tract infections (UTIs) and lower urinary tract symptoms (LUTS) and urinary incontinence; however, the causal relationship is considered complex. Both men and women with UTIs have higher rates of urinary incontinence than people without UTIs (Buckley & Lapitan 2010; Shamliyan et al. 2007). It is unclear whether UTIs increase the risk of later urinary incontinence, if urinary incontinence increases the risk of UTIs, or if both UTIs and urinary incontinence are a result of a different underlying problem (Milsom et al. 2009).

Impaired physical functioning

Mobility impairment, history of falls, arthritis, the need to use a walking aid, dizziness and limitations in daily activities have all been associated with increased risk of urinary incontinence (Buckley & Lapitan 2010). The relationship between these factors and urinary incontinence is unclear; urinary incontinence may be a direct outcome of not being able to get to the bathroom in time and removing clothing, or a result of underlying physiological issues that accompany ageing. An alternate view is that this should not be considered incontinence at all, given the individual may have full control over their bladder or bowel, but lack the physical capacity to get to the toilet or prepare to use the toilet in time.

Physical activity

The relationship between incontinence and physical activity remains unclear. Anecdotally, stress urinary incontinence is often associated with physical activity, particularly in women. However, the analytical evidence to support this is limited.

When controlling for other factors such as age and number of children, the association between urinary incontinence and physical activity weakens, and in many cases physical activity appears to be a protective factor (Shamliyan et al. 2007). For instance, after controlling for other potential risk factors, Danforth et al. (2007) found that in women aged 54–79, increasing physical activity was associated with decreasing incidence of urinary incontinence. It was also associated with decreasing stress urinary incontinence.

There is limited research about the association of physical activity and fecal incontinence. One study found that physical activity reduced fecal urgency by 70%, when controlling for other factors (Bradley et al. 2005; cited in Shamliyan et al. 2007); however, this is yet to be repeated.

Diabetes mellitus

Urinary incontinence has been shown to be 50–200% more common in women with Type 2 diabetes than women with normal blood sugar levels. There is less research investigating the relationship between Type 1 diabetes and incontinence; however, preliminary results suggest Type 1 diabetes also increases the risk of incontinence (Phelan et al. 2009) (see Boxes 3.3 and 3.4).

Box 3.3: Management of comorbid conditions

What are comorbid conditions?

The terms ‘comorbidity’ and ‘comorbid conditions’ refer to the presence of more than one medical condition in an individual. For example, a person with diabetes may also have incontinence.

Can the management of comorbid conditions affect incontinence?

In many cases, yes. Research supports the effective management of some comorbid conditions as a method of decreasing the prevalence or symptoms of incontinence (Landefeld et al. 2008). This includes the effective management of:

- obesity
- diabetes mellitus
- irritable bowel syndrome, inflammatory bowel disease, diarrhoea and constipation
- neurological conditions
- impaired mobility.

More research is required to understand the exact reasons behind the association of incontinence with these factors. Understanding these reasons may help to identify further strategies to reduce the risk of developing incontinence, or minimise symptoms.

Neurological disorders

Neurological disorders, including stroke, Parkinson disease, multiple sclerosis and spinal cord injuries, have been associated with urinary and fecal incontinence (Khan et al. 2009; Shamliyan et al. 2007). It is unclear whether this is due to the physical limitations that accompany these disorders, or whether there are underlying physiological or neurological issues causing incontinence. Much of this evidence is based on small studies or anecdotal evidence.

Cognitive impairment (including dementia)

There is strong evidence supporting the association between dementia and incontinence, both urinary and fecal. The risk of developing incontinence increases with the severity of dementia (Milsom et al. 2009).

The relationship between mental status or cognitive impairment and incontinence is less clear. Although many reports have found an increased risk of urinary incontinence with worsening mental state or lower cognitive functioning, once these results were adjusted to control for potential confounding factors, the association weakened (Milsom et al. 2009). Further study is required in this area to understand this relationship in more depth.

Box 3.4: High body mass index— a major modifiable risk factor

What is a modifiable risk factor?

Modifiable risk factors are those that people can change. It is important to recognise these as distinct from risk factors that people cannot change (for example, age, family history).

What is BMI?

Obesity can be identified using body mass index (BMI). BMI is a ratio of weight to height, and is a guide to whether a person is a healthy weight or not. Using the World Health Organization's (WHO 2000) definitions, BMI weight ranges are underweight (< 18.5), healthy (18.5 < 25), overweight but not obese (25 < 30) and obese (30 or more).

Limitations with BMI include that it does not reflect body fat distribution, cannot distinguish between muscle and fat distribution, and it may not be suitable to particular ethnic groups (such as Asia-Pacific) or age groups (for example, children) (AIHW 2012c).

What is the association between BMI and incontinence?

Subak et al. (2009) suggest that for every five-unit increase in BMI, there is a 20–70% increase in risk of urinary incontinence. The mechanism for the relationship is unclear. Milsom et al. (2009) suggest that the extra weight on the pelvic floor creates increased pressure, leading to chronic strain, stretching or weaknesses of these muscles. Obesity has also been associated with fecal incontinence in women, but not men (Whitehead et al. 2009).

Can weight loss reduce the risk of incontinence or improve incontinence symptoms?

Evidence strongly supports weight reduction, particularly in women, as a method for reducing the risk of incontinence and leading to improvements in incontinence symptoms (Brown et al. 2006; Burgio et al. 2007; Hunskaar 2008; Shamliyan et al. 2007; Subak et al. 2009). High-intensity physical activity may increase the risk of incontinence, but moderate physical activity can reduce the risk of urinary incontinence (Brown et al. 2006; Phelan et al. 2009).

What is the relationship between BMI, diabetes and incontinence?

Being overweight or obese can contribute to the development of Type 2 diabetes. Both diabetes and obesity are risk factors for urinary incontinence in women (Milsom et al. 2009; Shamliyan et al. 2007). The evidence for these relationships in men is less clear—possibly because risk factors in males are less studied than in females.

Type 2 diabetes may increase the chances of urge urinary incontinence in women by 20% compared with women without Type 2 diabetes (Danforth et al. 2009). The strength of the association between diabetes and urinary incontinence increases the longer one has diabetes (Milsom et al. 2009)—after 5 years of diabetes, women are at a 50% greater risk of severe urinary incontinence than women without diabetes. Some evidence also suggests that diabetes is associated with fecal incontinence (Shamliyan et al. 2007).

Although uncertain, possible mechanisms by which diabetes leads to incontinence include increased intra-abdominal pressure from excess weight, or microvascular, physiological and neurological complications accompanying diabetes (Milsom et al. 2009; Phelan et al. 2009).

How does this relate to the Australian population?

In 2007–08, 1 in 4 Australian adults (aged 18 and over) were obese (25%) and almost 1 in 10 children (aged 5–17) were obese (8%), representing almost 3 million people. Almost 900,000 Australians (4.1% of the population) have been diagnosed with diabetes at some time in their lives—Type 2 diabetes comprises 85–90% of all cases and is linked to obesity (AIHW 2012c). All of these people are at an increased risk of developing incontinence.

Diarrhoea and constipation

People with diarrhoea and loose stools, including those with irritable bowel syndrome and illnesses that cause diarrhoea, are at increased risk of fecal incontinence (Norton et al. 2005; Rey et al. 2009; Rømmen et al. 2012; Whitehead et al. 2009). Evidence also suggests that constipation and chronic straining can contribute to the development of urinary incontinence (Shamliyan et al. 2007).

Menopause

Conclusive evidence regarding the association between menopause and urinary incontinence has not been established. Shamliyan et al. (2007) report that the increased prevalence of urinary incontinence during menopausal years is often assumed to be due to hormonal changes. Although menopause has been significantly associated with urinary incontinence, it is also possible that the ageing process is the more likely associated factor than menopause itself. A higher risk of urinary incontinence has also been associated with hormone replacement therapy (including estrogen replacement therapy) (Buckley & Lapitan 2010; Shamliyan et al. 2007).

Effects on emotional wellbeing and quality of life

Incontinence may be a symptom of an underlying illness, disease or mental health issue, a side effect of treatment or a health issue in its own right for an individual. People who suffer from incontinence generally experience more severe disability and health problems than other people with disability. Regardless of the cause of incontinence, the experience of incontinence may affect emotional and psychological wellbeing, quality of life and ability to participate in normal activities of daily living.

However, it is important to recognise that incontinence can be managed effectively and does not always affect quality of life, wellbeing or daily activities. Variables such as type, severity and frequency of incontinence, success of any treatment and the effect of any attempted management strategies, quality of social support and individual differences in coping skills may all influence wellbeing outcomes (Landefeld et al. 2008).

Mental health outcomes

People who experience incontinence often report their experience as embarrassing, upsetting and distressing (Bogner et al. 2011). Feelings of worthlessness and helplessness may accompany incontinence (Farage et al. 2008).

Anxiety and depression may sometimes be associated with incontinence (Coyne et al. 2012; Felde et al. 2012). Recent research has focused on the causal relationship between incontinence and psychological wellbeing—do mental health outcomes, such as anxiety, cause incontinent episodes or, alternatively, does incontinence cause mental health outcomes?

According to Bogner et al. (2011), among community-living adults, urinary incontinence with condition-specific functional loss (such as restricting social activities) predicted the onset of anxiety disorders. This anxiety may be due to the possibility of having an 'accident' or not having ready access to toilet facilities. Similarly, urinary incontinence with condition-specific functional loss also predicts psychological distress among community-living adults (deVries et al. 2011).

Conversely, in a separate longitudinal study, major depression predicted the onset of urinary incontinence in a population-based sample of at-risk community-dwelling women, but incontinence did not predict the onset of depression (Melville et al. 2009).

Quality of life

A high proportion of people with incontinence report it has a negative effect on their quality of life. The severity of the symptoms appears to be a mediating factor on the impact it has—people with the most severe symptoms were most likely to be adversely affected, and more likely to ask for help (Bordeianou et al. 2008; Lasserre et al. 2009).

In Australia, Kwong et al. (2010) found that men with incontinence reported lower quality of life scores—with the biggest effect on the physical rather than the mental component of the quality of life scale—than men who were continent. This difference remained significant after controlling for the effects of age, number of comorbidities, and enlarged prostate and prostate cancer between the groups. In Australian community-living women, incontinence was associated with lower psychological wellbeing scores than those without incontinence, after controlling for age, systemic hormone therapy use, menopause status, smoking status and regular exercise (Botlero et al. 2010).

4 Severe incontinence in Australia

This chapter presents prevalence estimates of the Australian population with severe incontinence, and describes some characteristics and experiences of these people and their carers. Information about the level of assistance needed to manage bladder or bowel control and continence aids is also discussed.

Data source

The primary data source for this analysis is the 2009 SDAC confidentialised unit record file (CURF). This national population-based survey comprised more than 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 3 months or more). It excluded people living in correctional institutions. People in both urban and rural areas in all states and territories were included, except those living in very remote areas.

A statistical process known as weighting was conducted to infer results for the total Australian population. For further details regarding the SDAC and the survey methodology (including weighting), see <http://bit.ly/YvdiQu>.

The SDAC is a cross-sectional sample survey—therefore, sampling errors are associated with all estimates. Issues of statistical significance are highlighted, where relevant. Given the design of the survey, it is possible to identify associations between factors, but not draw conclusions regarding causality.

Definitions

In this analysis, and the two previous reports released by the AIHW on incontinence (AIHW 2006, 2012c), a person with severe incontinence is defined as someone who always or sometimes needs assistance with bladder or bowel control and/or uses continence aids (see Box 2.1 for further details). This underestimates the total population who experience incontinence in Australia, as it does not include people with milder symptoms (not classified as 'severe' by definition). Note that SDAC respondents were not asked to differentiate between urinary and fecal incontinence.

In the SDAC, all people who were asked about their level of need for assistance with managing their own bladder or bowel control and all people asked about whether they used continence aids had a disability—therefore, all people with severe incontinence had a disability. In this report, for clarity, the phrase 'with disability' will be omitted when referring to people with incontinence-related issues. For example, people with disability and severe incontinence will be referred to as 'people with severe incontinence'. This differs from the *Australian incontinence data analysis and development* (AIHW 2006) report where people with severe incontinence, people who need assistance with managing their own bladder or bowel control and people who use continence aids are referred to as 'people with disability and severe incontinence'—see Box 2.1.

In most rates presented in this chapter, the denominator used is 'all persons with disability'. This is because people with incontinence-related issues all have disability, ensuring the comparison of 'like' population groups. Also, because the numbers of people experiencing bladder or bowel control issues or using continence aids as a proportion of the total Australian population is extremely small, meaningful comparisons and conclusions would be difficult to extrapolate from the data if the denominator was the total population. The one exception is the reporting of the prevalence of severe incontinence in Australia—in this instance, the denominator is the Australian population as defined by the 2009 SDAC. Further definitions of incontinence-related concepts and terms are in Box 2.1.

How many people does it affect?

Prevalence

In 2009, as defined in the SDAC, 1.5% of the total Australian population (316,500 people) experienced severe incontinence. In 2003, 1.4% of the Australian population (284,500 people) reported severe incontinence (AIHW 2006). Most people suffering from severe incontinence needed help with other activities as well; in 2009, only 46,000 people aged 5 and over living in households reported that continence management was the only activity they needed assistance with (see Box 4.1).

Along with the lower estimate above, the 2006 AIHW report also reported that in 2003, '545,000 people, or 2.8% of the Australian adult population, experience severe incontinence', This higher figure was derived from combining estimates in the SDAC and data in the SAHOS to identify people not picked up in the SDAC who suffered from 'very severe, severe or frequent incontinence'. The SAHOS has not collected incontinence-related information since 2004 and changes in patterns of incontinence suggest that assumptions based on the 2004 SAHOS data would not be well founded, so the AIHW has not updated the higher estimate.

Box 4.1: People with severe incontinence only

Most people who had severe incontinence also needed help with other activities such as eating, mobility or dressing; however, there was a small group of people who only needed help because of their incontinence.

In 2009, there were 46,000 people aged 5 and over living in households whose only activity they needed help with was continence management—that is, they always or sometimes needed help with managing their bladder or bowel control or used continence aids, but did not need help with any other activity. Of this group:

- 3 in 4 people were female (73.5%)
- more than half were aged 5–64 (54.8%)
- 1 in 3 people said they could not go out as often as they would like (32.6%), compared with more than half of those people with severe incontinence and who needed help with other tasks (56.7%)
- the labour force participation rate for those of working age (15–64) was 39.8%—considerably lower than that for people without disability (83.2%), as measured in the SDAC.

The prevalence of severe incontinence varied significantly between the household and cared accommodation populations (see Table 4.1). Less than 1.0% of the Australian household population experienced severe incontinence, with a slightly higher prevalence reported for females (1.2%) than males (0.7%). Conversely, 3 in 4 people living in cared accommodation experienced severe incontinence (74.3%). Again, females (77.5%) were more likely to experience severe incontinence than males (67.6%).

Age was associated with increasing prevalence of severe incontinence. For the total Australian population, the prevalence was 12 times greater in those aged 65 and over (7.2%) than those aged 0–64 (0.6%). For people aged 85 and over, the prevalence was much greater (24.5%).

Table 4.1: Prevalence of severe incontinence, by residential status, sex and age, 2009 (%)

	Male	Female	Persons
Age group (years)		**Households**	
0–39	0.5	0.5	0.5
40–64	0.4	0.9	0.6
65–84	1.9	3.7	2.9
85+	*5.7	10.3	8.7
0–64	0.5	0.6	0.5
65+	2.2	4.5	3.5
Total	*0.7*	*1.2*	*0.9*
		Cared accommodation	
0–39	*40.0	*47.0	42.1
40–64	53.5	66.7	59.0
65–84	71.3	77.4	75.1
85+	70.7	78.8	76.9
0–64	51.1	64.5	56.5
65+	71.0	78.3	76.1
Total	*67.6*	*77.5*	*74.3*
		Australian population	
0–39	0.5	0.5	0.5
40–64	0.5	1.0	0.7
65–84	3.3	5.9	4.7
85+	16.5	28.4	24.5
0–64	0.5	0.7	0.6
65+	4.5	9.4	7.2
Total	**1.0**	**2.0**	**1.5**

* Estimate has a relative standard error of 25–50% and should be used with caution.

Notes

1. 'Severe incontinence' is defined as always or sometimes needing assistance with managing bladder or bowel control and/or uses continence aids.

3. The denominator used to calculate the prevalence estimates is the 2009 ABS SDAC CURF Australian population in households, cared accommodation and total Australian population, as appropriate.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Level of core activity limitation or restriction

The following section outlines the differences in core activity limitations and restrictions experienced by people with severe incontinence compared with people with disability but without severe incontinence (see Box 4.2). This latter group may still experience symptoms of incontinence, but not to the same extent as those classified as experiencing severe incontinence. The limitations and restrictions identified may also be attributed to the presence of other health or disability issues along with the problems caused by incontinence itself. As previously mentioned, all people identified as having severe incontinence have a disability, that is, a core activity limitation or schooling/employment restriction.

Box 4.2: SDAC definition of core activity limitations and restrictions

Core activity limitations

The SDAC defines core activities as communication, mobility and self-care. There are four levels of core activity limitation, determined by whether a person needs help, has difficulty, or uses aids or equipment with any of the core activities. The levels are:

- profound: the person is unable to do, or always needs help with, a core activity task
- severe: the person sometimes needs help with a core activity task, has difficulty understanding or being understood by family or friends or can communicate more easily using sign language or other non-spoken forms of communication
- moderate: the person needs no help, but has difficulty with a core activity task
- mild: the person needs no help and has no difficulty with any of the core activity tasks, but uses aids or equipment, cannot easily walk 200 metres, cannot walk up and down stairs without a handrail, cannot easily bend to pick up an object from the floor, cannot use public transport or can use public transport but needs help or supervision, or needs no help or supervision but has difficulty using public transport.

A person's overall activity limitation is determined by their highest level of limitation in the three core activities.

Employment and schooling restrictions

An employment restriction is determined for people aged 15–64 with one or more disabilities if, because of their disability, they: are permanently unable to work, are restricted in the type of work they can or could do, need or would need at least 1 day a week off work on average, are restricted in the number of hours they can or could work, require employer-provided special equipment, modifications to the work environment or special arrangements, require assistance from a disability job placement program or agency, need or would need ongoing assistance or supervision or would find it difficult to change or get a better job.

A schooling restriction is determined for people aged 5–20 with one or more disabilities if, because of their disability, they: are unable to attend school, attend a special school, attend special classes at an ordinary school, need at least 1 day a week off school on average or have difficulty at school.

Source: ABS 2010

Table 4.2 demonstrates a strong association between the severity of core activity limitation or restriction and incontinence status. A large majority (91.0%) of people with severe incontinence also had a severe or profound core activity limitation (see Figure 4.1). In comparison, 1 in 4 (26.1%) people without severe incontinence had a severe/profound core activity limitation.

Table 4.2: All people with disability: disability status, by whether has severe incontinence, 2009

	Has severe incontinence		Does not have severe incontinence	
	Number	Per cent	Number	Per cent
Severity of core activity limitations or restrictions				
Has disability and profoundly limited in core activities	230,716	72.9	385,101	10.6
Has disability and severely limited in core activities	57,195	18.1	558,761	15.4
Has disability and moderately limited in core activities	24,154	7.6	623,665	17.2
Has disability and mildly limited in core activities	*4,386	*1.4	1,195,420	33.0
Has disability and not limited in core activities but restricted in schooling or employment	–	–	332,929	9.2
Has disability and not limited in core activities or restricted in schooling or employment	–	–	525,427	14.5
Total	**316,451**	**100.0**	**3,621,303**	**100.0**

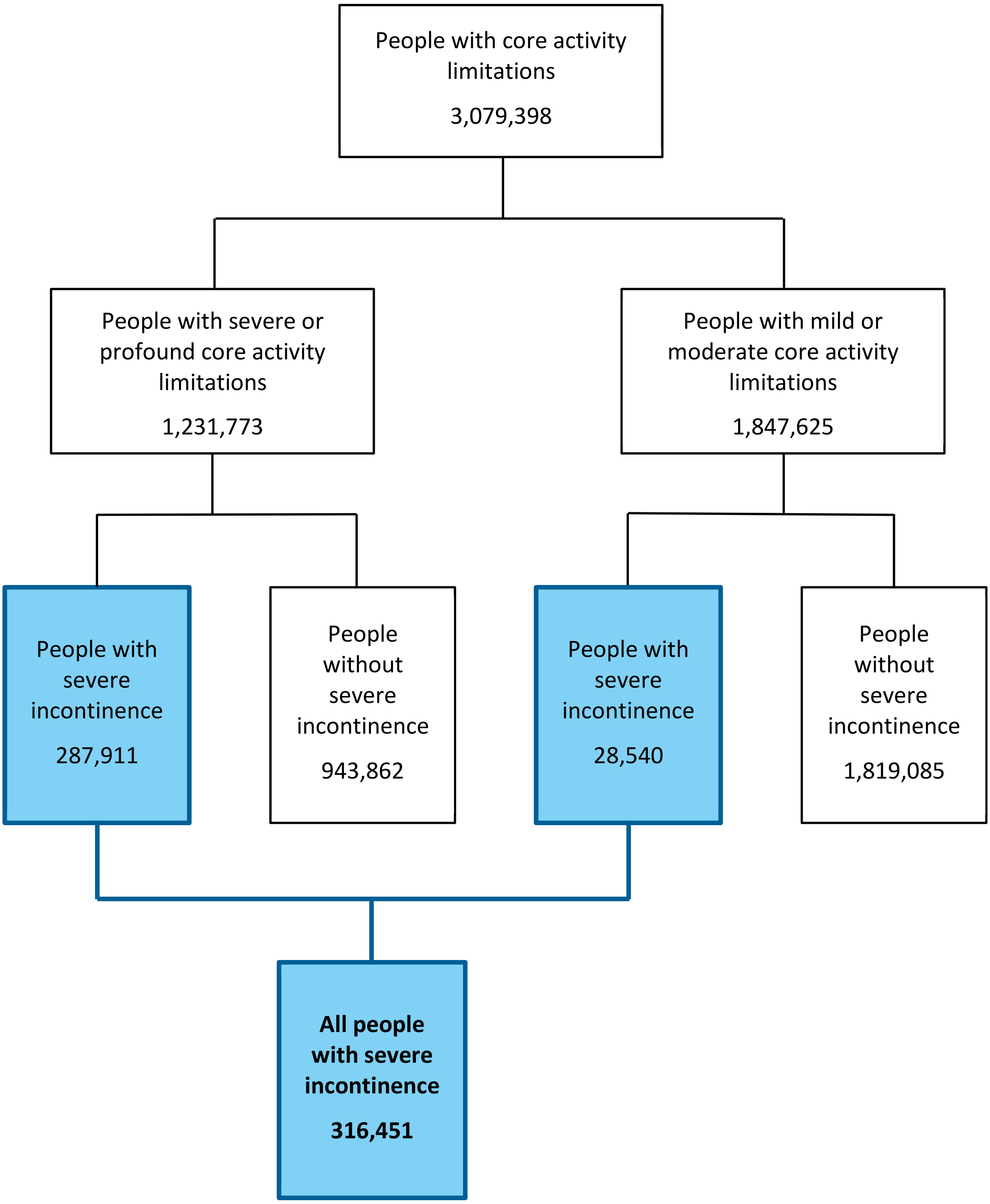
* Estimate has a relative standard error of 25–50% and should be used with caution.

Source: AIHW analysis of 2009 ABS SDAC CURF.

There was a significant association between the three types of core activity limitations and incontinence status (see Table 4.3). People with severe incontinence were 15 times as likely to have profound self-care limitations (65.6%), 7 times as likely to have profound mobility limitations (59.1%) and 12 times as likely to have profound communication limitations (20.8%) when compared with people without severe incontinence (4.5%, 8.5% and 1.7% respectively) (see Table 4.3). Alternatively, people without severe incontinence were much more likely to have no self-care, mobility or communication limitation than people with severe incontinence.

Characteristics of people with severe incontinence in households

Overall, 123,400 females (6.4% of females with disability) and 71,900 males (3.9% of males with disability) reported severe incontinence. This equates to about 2 in 3 people (63.2%) with severe incontinence being female.



Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 4.1: Relationship between severe incontinence and severity of core activity limitations, 2009

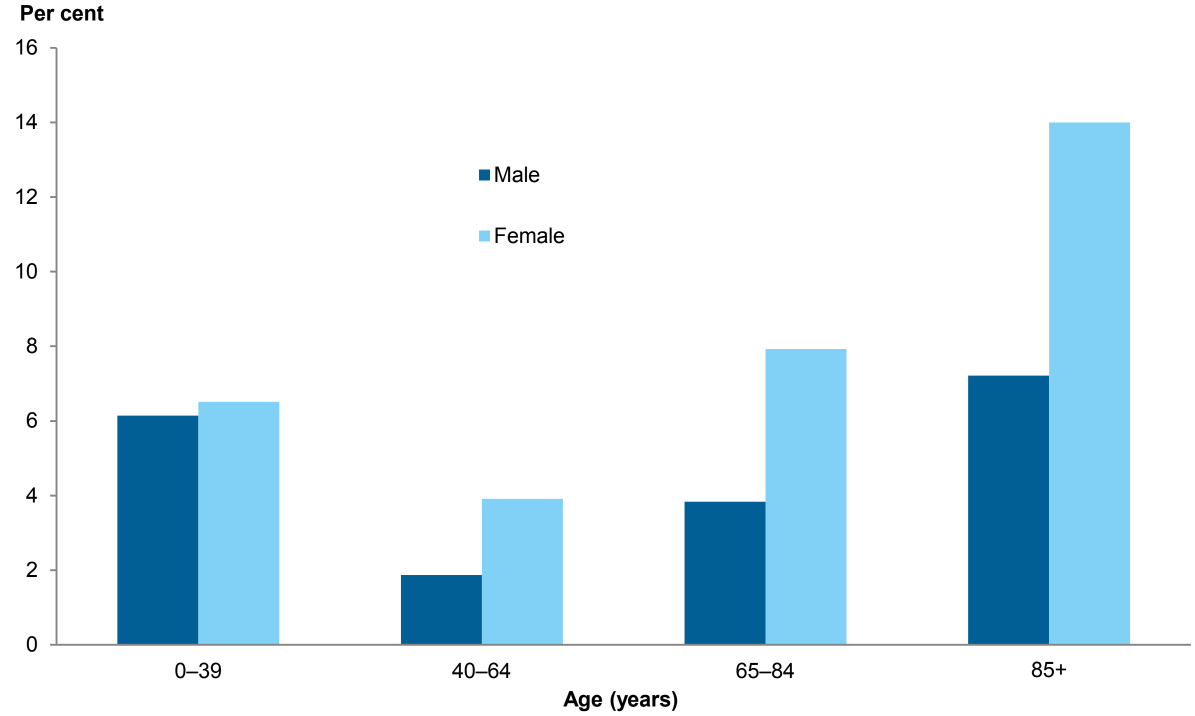
Table 4.3: All people with disability: type and severity of core activity limitations, by incontinence status, 2009

	Severe incontinence		Does not have severe incontinence	
	Number	**Per cent**	**Number**	**Per cent**
Level of self-care limitation				
Profound	207,443	65.6	161,308	4.5
Severe	70,385	22.2	254,091	7.0
Moderate	32,136	10.2	458,750	12.7
Mild	6,487	2.0	99,438	2.7
No self-care limitation	–	–	2,647,715	73.1
Level of mobility limitation				
Profound	187,178	59.1	308,062	8.5
Severe	59,652	18.9	449,457	12.4
Moderate	25,265	8.0	473,854	13.1
Mild	33,960	10.7	1,168,144	32.3
No mobility limitation	10,395	3.3	1,221,786	33.7
Level of communication limitation				
Profound	65,756	20.8	62,226	1.7
Severe	71,844	22.7	131,598	3.6
Moderate	9,545	3.0	68,332	1.9
Mild	24,095	7.6	491,725	13.6
No communication limitation	145,211	45.9	2,867,422	79.2
All persons	**316,451**	**100.0**	**3,621,303**	**100.0**

Note: Components may not add to total due to rounding.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

A much larger proportion of people aged 0–39 living in households experienced severe incontinence (6.3%) than those aged 40–64 (2.9%) (Figure 4.2). This is likely due to the inclusion of children who are not yet toilet trained or experience nocturnal enuresis (night-time bedwetting) in the 0–39 age group. Usually these children would not be considered incontinent; however, by the definition used in this report they are included in the population with severe incontinence due to difficulties in excluding children from the residential care population. There were 6,700 children aged 0-4 identified as suffering from severe incontinence (3.4% of all people in households suffering from severe incontinence).



Note: See Appendix Table A1 for data in this figure.

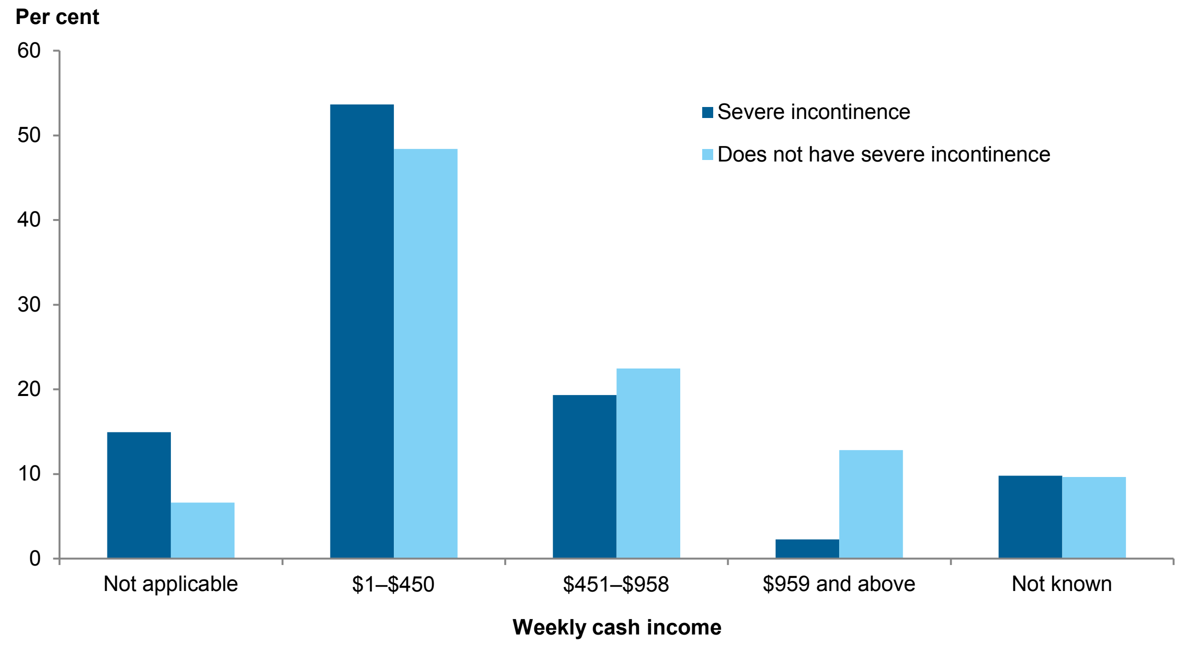
Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 4.2: Proportion of people living in households who have severe incontinence, by age and sex, 2009

In 2009, about 1 in 20 people living in households in major cities (5.4%) and inner regional areas (5.3%) experienced severe incontinence, compared with 1 in 27 people in other areas (3.7%). Severe incontinence was experienced by the same proportion of people regardless of their country of birth—5.1% of people born in Australia, 5.4% of people born in main-English speaking countries and 5.1% of people born in other countries. Similarly, there were no significant differences between the main language spoken at home and the proportion of people with severe incontinence—about 5.1% of people whose main language at home was English experienced severe incontinence, as did 5.6% of people whose main language spoken at home was not English.

The characteristics of people living in households with severe incontinence compared with people without severe incontinence was also analysed (see tables A1 and A2). Any differences between these populations may be a result of incontinence status, the difference in severity of core activity limitations as previously described, or other factors associated with incontinence status.

Total weekly cash income and the source of this income were associated with incontinence status (see Figure 4.3). More than half the population with severe incontinence (53.7%) reported earning $1–$450 per week, compared with 48.4% of people without severe incontinence and 48.7% of people with any disability. Alternatively, people with severe incontinence were one-sixth as likely to earn $959 or more per week (2.3%) as people without severe incontinence (12.8%) and one-fifth as likely to earn that much as people with any disability (12.3%).



Notes

1. See Appendix Table A2 for this figure.
2. Income categories correspond to decile groupings released by the ABS.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

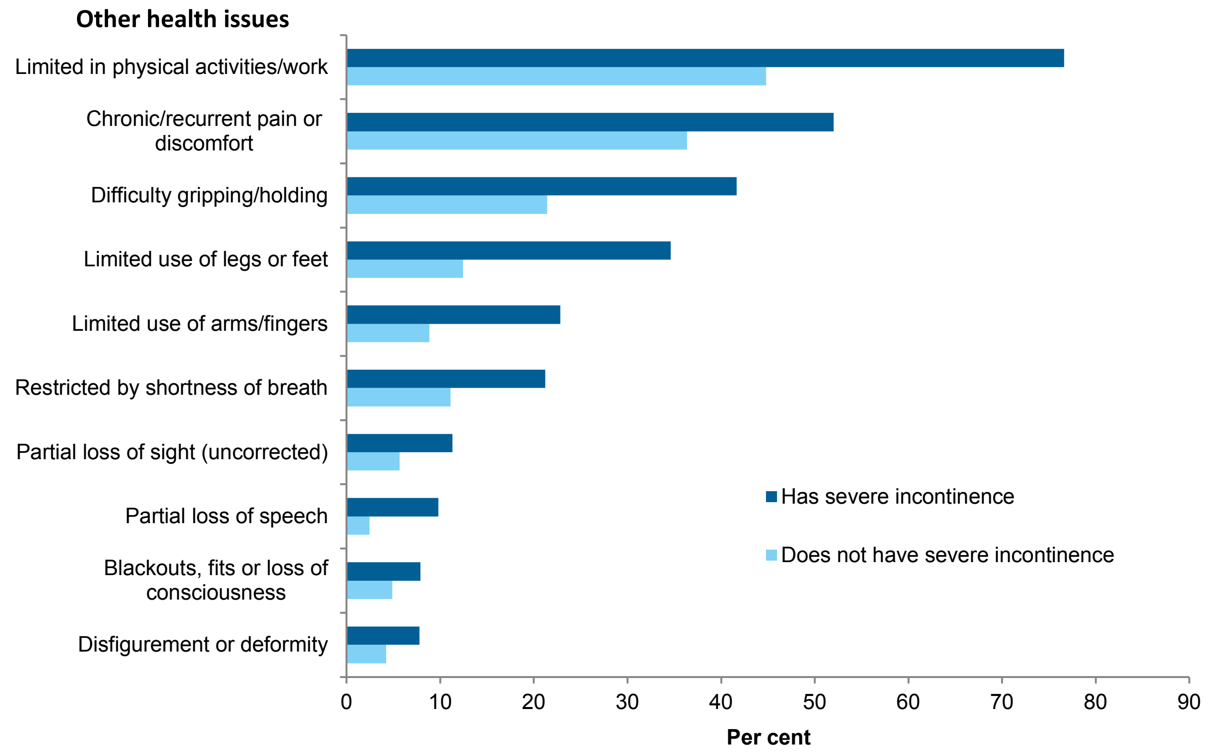
Figure 4.3: Proportion of people with disability aged 15 and over living in households, weekly cash income groupings, by incontinence status, 2009

The differences in earnings were likely to be due to the differences in the source of earnings—people with severe incontinence were more likely to receive a government pension, allowance or benefit as their main source of cash income than people without severe incontinence and people with any disability (64.2%, 51.2% and 51.9%, respectively). People with severe incontinence were older on average than other people with disability (see Table A1), which is likely to result in a larger number of pension, allowance and benefit recipients.

The main types of government assistance received by people with severe incontinence were the Age Pension (36.4%) and Disability Support Pension (21.4%). Additionally, people without severe incontinence were about 4 times as likely to receive their cash income from an employer than people with severe incontinence (23.6% and 6.3%, respectively).

Other health issues for people with severe incontinence

As mentioned earlier, it is difficult to distinguish between problems caused directly by severe incontinence and those caused by other disability and health conditions that accompany incontinence. Other health issues or limitations experienced by people with severe incontinence may contribute to their incontinence or result from their incontinence. For example, a person may have severe functional incontinence because they have limited mobility, or a person's severe incontinence may cause chronic discomfort.



Notes

1. See Appendix Table A3 for data in this figure.

2. The denominator used to calculate the proportions was ‘all people with severe incontinence’ and ‘all people without severe incontinence’.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 4.4: Proportion of people with disability aged 15 and over living in households, by other health issues, limitations or restrictions and incontinence status, 2009

Overall, people with severe incontinence experienced more health issues, restrictions or limitations than people without severe incontinence (Figure 4.4). For example, 2 in 3 people (76.6%) with severe incontinence were restricted or limited in their physical activity or physical work, compared with 44.8% of people without severe incontinence. As well, 1 in 3 people (41.6%) with severe incontinence had difficulty gripping or holding things, compared with 1 in 5 people (21.4%) without severe incontinence.

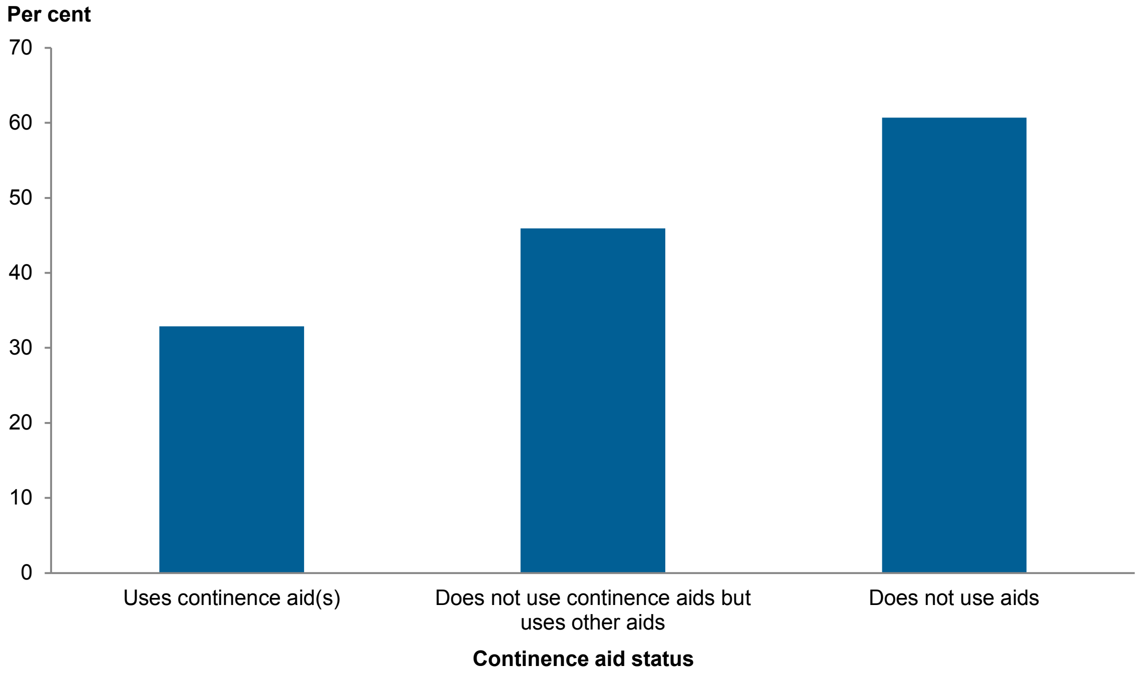
Influence of incontinence on the individual

The following analysis compares aspects of everyday life and participation of people living in households with severe incontinence with those for people without severe incontinence. Severe incontinence cannot be attributed as the only cause of any differences between these two populations—it is likely to be a combination of factors, such as other aspects of disability.

Labour force participation

Labour force participation is the proportion of people aged 15–64 who are working, or able to work but who are currently unemployed and looking for work. In 2009, the labour force participation rate was lower for those with severe incontinence (26.1%) than those without (55.8%) (see Table A4). It is likely that this difference is related to the finding that 91.0% of people with severe incontinence also reported a severe or profound core activity limitation—in 2009, labour force participation for all people of working age with disability was 54.8%, and 31.6% for people of working age with severe or profound core activity limitation. In comparison, according to the 2009 SDAC, the labour force participation rate for people without disability (aged 15–64) was 83.2%.

The two aspects of severe incontinence—needing help with bladder or bowel control and using continence aids—differ in their effects on labour force participation. For instance, it is to be expected that people who do not need help with bladder or bowel control are more likely to participate than those who do need help, even if they use continence aids. About 1 in 5 (20.4%) people who always or sometimes needed help with managing their bladder or bowel control were participating in the labour force, compared with 2 in 5 (42.3%) people who did not need help but had difficulty with managing their bladder or bowel control (AIHW 2012a). As shown in Figure 4.5, of people with disability, the labour force participation was considerably lower for those who used continence aids (32.9%) than for those who did not use continence aids but used other aids (45.9%) and those who did not use aids at all (60.7%).



Note: See Appendix Table A5 for data in this figure.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 4.5: Labour force participation rate of people with disability aged 15–64 living in households, by whether uses continence aids, 2009

Social participation

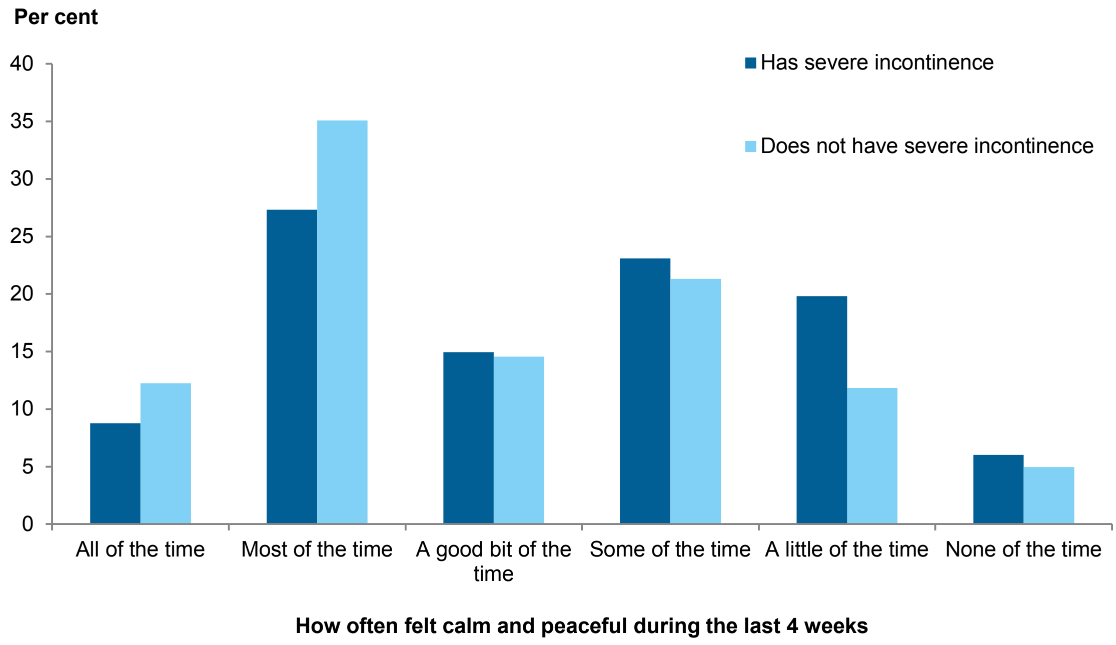
Individuals with incontinence describe their symptoms as embarrassing, bothersome and anxiety-provoking (Bogner et al. 2011; Kwong et al. 2010). These feelings may influence their motivation, willingness or confidence to go out and participate in community or social activities.

According to the 2009 SDAC, more than half of people (52.4%) with severe incontinence could not go out as often as they would like—more than two-thirds of whom (68.2%) said that this was because of their own disability or condition (see Tables A6 and A7). In comparison, 1 in 4 people (26.8%) without severe incontinence reported they could not go out as often as they would like, and 43.6% said it was because of their own disability or condition. Just under 5,000 people (2.8%) with severe incontinence reported that they could not go out at all, compared with just 0.9% of people without severe incontinence.

Health and emotional wellbeing

In the SDAC, some people aged 15 and over with disability were asked to assess their own emotional and physical wellbeing. In general, those with severe incontinence reported poorer emotional and physical wellbeing than those without severe incontinence (see figures 4.6 to 4.9). In the 4 weeks before the interview, people with severe incontinence:

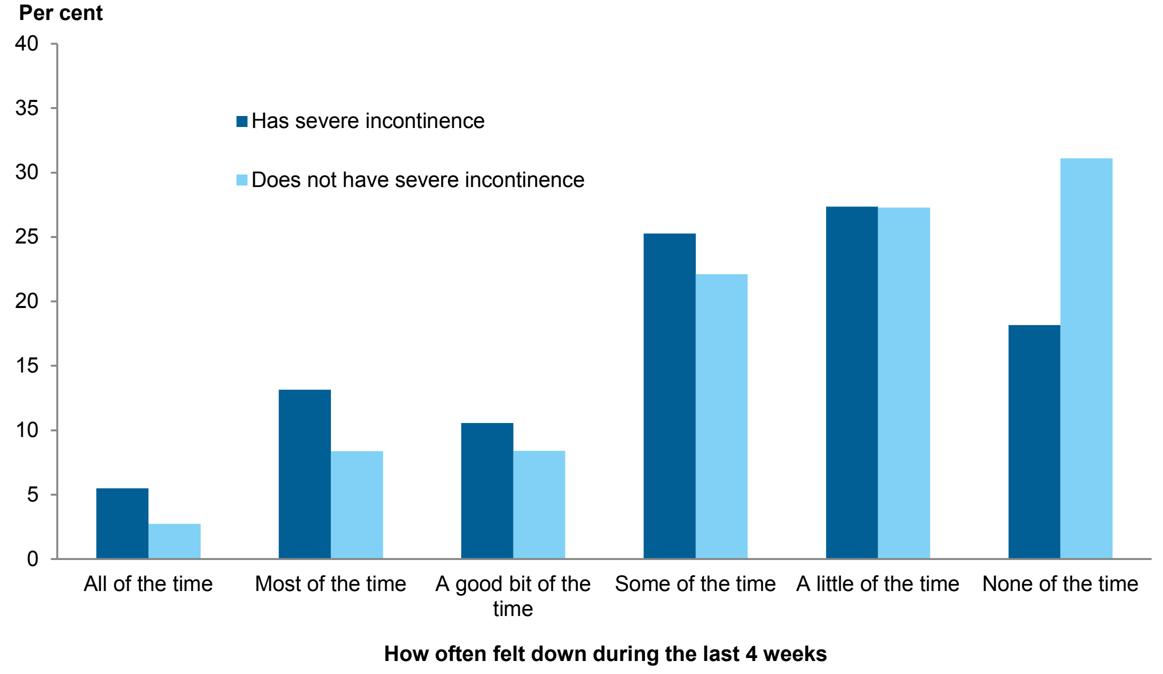
- were less likely to feel calm and peaceful all of the time (8.8%) or most of the time (27.3%) than people without severe incontinence (12.2% and 35.1%, respectively)
- were more likely to feel down all of the time (5.5%) or most of the time (13.2%), than people without severe incontinence (2.7% and 8.4%, respectively)
- were less likely to feel that they had a lot of energy all of the time (2.0%) or most of the time (8.9%) than people without severe incontinence (5.9% and 21.4%, respectively)
- were more likely to indicate that at no time did they feel that they had a lot of energy (27.4%) than people without severe incontinence (13.2%)
- were more likely to report fair (34.0%) or poor general health (22.2%) than people without severe incontinence (24.8% and 10.4%, respectively).



Note: See Appendix Table A8 for data in this figure.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

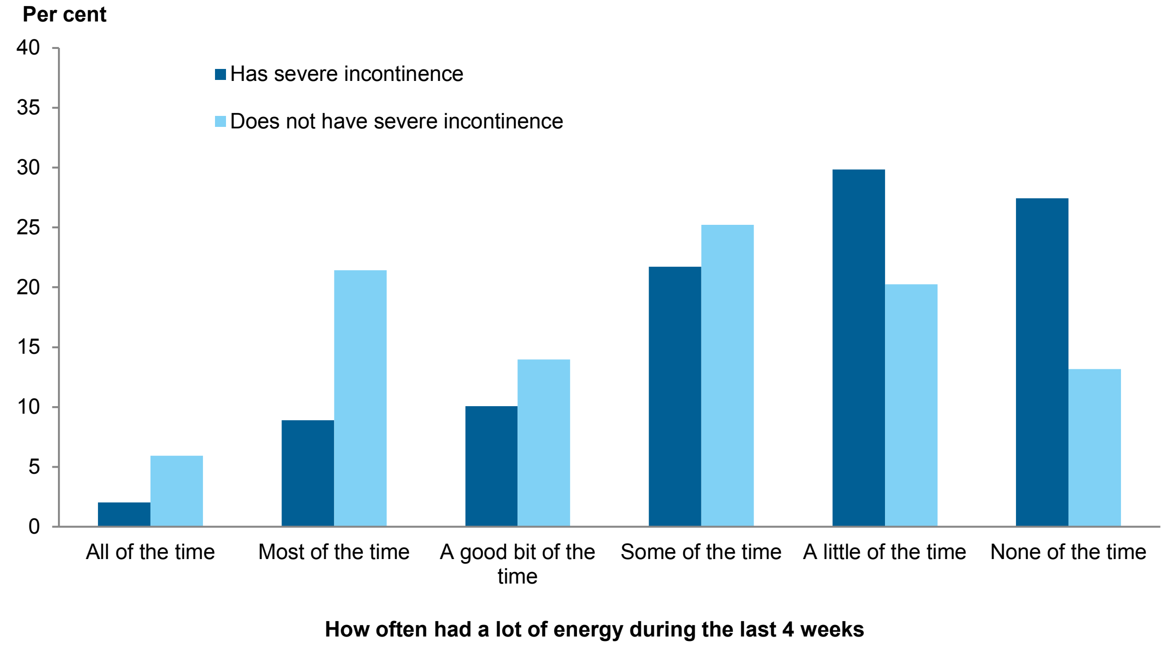
Figure 4.6: Proportion of people with disability aged 15 and over living in households, by how often they felt calm and peaceful during the last 4 weeks and incontinence status, 2009



Note: See Appendix Table A8 for data in this figure.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

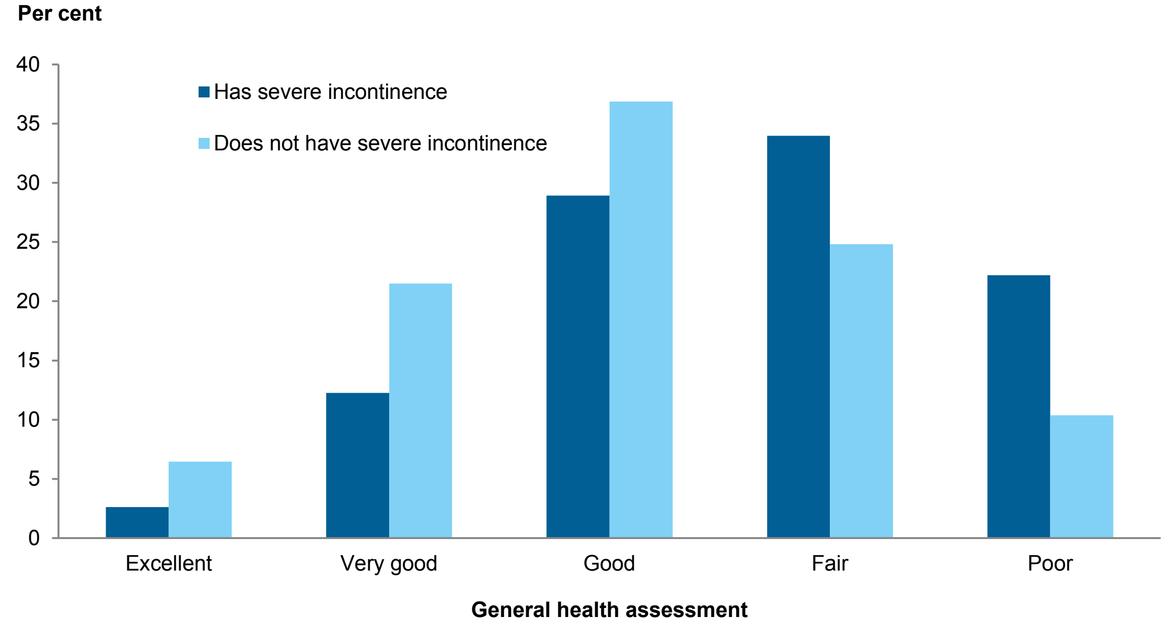
Figure 4.7: Proportion of people with disability aged 15 and over living in households, by how often they felt down during the last 4 weeks and incontinence status, 2009



Note: See Appendix Table A8 for data in this figure.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 4.8: Proportion of people with disability aged 15 and over living in households, by how often they felt they had a lot of energy and incontinence status, 2009



Note: See Appendix Table A8 for data in this figure.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 4.9: Proportion of people with disability aged 15 and over living in households, by self-assessed general health and incontinence status, 2009

Children with incontinence

In 2009, there were 30,100 children aged 5–19 with severe incontinence, representing about 1 in 10 (9.6%) children with disability. Of those children with severe incontinence, just over 12,000 used continence aids, representing 1 in 26 (3.8%) children with disability. Nearly all of the children who used continence aids had a severe/profound core activity limitation (see Table 4.4).

As presented in *Incontinence in Australia: prevalence, experience and cost* (AIHW 2012a), 91.2% of children (or 26,900) with severe incontinence and severe or profound core activity limitation attended school—40.5% attended ordinary school, 27.2% attended special school and 23.6% attended a special class in an ordinary school. When including all children with disability and severe incontinence, irrespective of their level of core activity limitation, 91.4% attended school—41.6% attended ordinary school, 23.2% attended special class and 26.6% attended a special school (see Table 4.5).

Table 4.4: Children aged 5–19 with disability, living in households, level of core activity limitation or restriction, by use of continence aids, 2009

	Uses continence aid(s)		Does not use continence aids but uses other aids		Does not use aid(s)		Total children	
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent
Incontinence status								
Has severe incontinence	12,051	100.0	6,524	8.4	11,501	5.1	30,076	9.6
Does not have severe incontinence	–	–	70,783	91.6	212,265	94.9	283,048	90.4
Severity of core activity limitation								
Severe/profound core activity limitation	11,481	95.3	42,935	55.5	96,747	43.2	151,163	48.3
Mild/moderate core activity limitation	**570	**4.7	19,268	24.9	49,594	22.2	69,432	22.2
Not limited in core activities but restricted in schooling	–	–	8,177	10.6	44,282	19.8	52,459	16.8
Not limited in core activities or restricted in schooling	–	–	6,928	9.0	33,143	14.8	40,071	12.8
Total children	**12,051**	**100.0**	**77,307**	**100.0**	**223,766**	**100.0**	**313,124**	**100.0**
Proportion of children with disability		**3.8**		**24.7**		**71.5**		**100.0**

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Note: Components may not add to total due to rounding.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table 4.5: Children aged 5–19 with disability, living in households, incontinence status, by school attendance, 2009

	Has severe incontinence		Does not have severe incontinence		Children with disability	
	Number	Per cent	Number	Per cent	Number	Per cent
Ordinary school	12,515	41.6	165,214	58.4	177,729	56.8
Special class	6,968	23.2	58,657	20.7	65,625	21.0
Special school	8,011	26.6	18,206	6.4	26,217	8.4
Total attending school	*27,494*	*91.4*	*242,077*	*85.5*	*269,570*	*86.1*
Not attending school (because of disability)	*1,891	*6.3	*4,450	*1.6	6,341	2.0
Not attending school (other)	**691	**2.3	36,521	12.9	37,212	11.9
Total not attending school	**2,582*	**8.6*	*40,972*	*14.5*	*43,554*	*13.9*
Total children	**30,076**	**100.0**	**283,048**	**100.0**	**313,124**	**100.0**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Note: Components may not add to total due to rounding.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Other incontinence-related issues

This section contains analysis of people with disability, the level of help they need to manage bladder or bowel control and whether they use continence aids. Individuals in this section include those with severe incontinence as defined by the SDAC, as well as those who may experience milder symptoms of incontinence (such as people who report they do not need help to manage their bladder or bowel control but have difficulty).

Help needed to manage bladder or bowel control

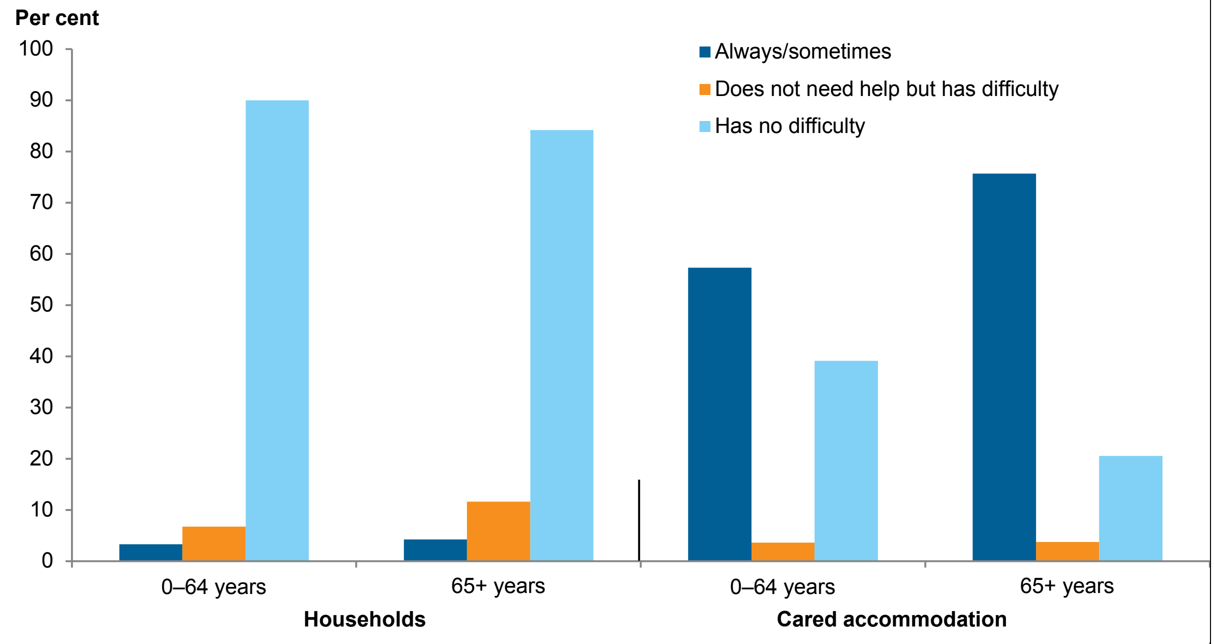
A person may have difficulty with managing their bladder or bowel control, regardless of whether they have severe incontinence or not. Managing bladder or bowel control is a complex function requiring coordination between the nervous system, urinary or gastro-intestinal system and the related muscular system. This coordination allows for the bladder or bowel to send the correct signal that it requires emptying to the brain via the nervous system, and for the brain to determine whether it is convenient to go to the toilet now or whether the person needs to 'hold on' (Wilkinson 2009). Once it is convenient, the person must then be able to physically access and use the toilet appropriately.

There can be many reasons a person has difficulty or needs help with managing their bladder or bowel control—for example, they may have a physical limitation that stops them from being able to manage their bladder or bowel control appropriately. Cognitive limitations, such as dementia or an intellectual disability, may also affect a person's ability to learn or remember how to manage their own bladder or bowel control. An acquired brain injury can interfere with the signals between the brain and bladder/bowel, affecting a person's ability to sense when they need to empty their bladder or bowel.

In 2009, 139,000 (3.7%) people living in households always or sometimes needed help or supervision in managing their own bladder or bowel control—more than half of whom were female (56.7%) and almost one-third of whom were aged 65–84 (30.1%). People aged 0–39 made up the highest proportion of people who always or sometimes needed help or supervision with managing their bladder or bowel control (36.9%). It is likely that children who are not toilet-trained or who experience night-time bedwetting are contributing to this high proportion (6,500 children aged 0–4 were identified in the survey as needing help with managing bladder or bowel control—4.7% of all persons in households needing this help). Usually these children would not be considered incontinent; however, by the definition used in this report they are included in the population with severe incontinence due to difficulties in excluding children from the residential care population.

Just over 9 in 10 people (143,300, or 90.8%) in cared accommodation were aged 65 and over, of whom 3 in 4 (75.7%) always or sometimes needed help or supervision with managing their bladder or bowel control. More than 3 in 4 people in cared accommodation who always or sometimes needed help were female (76.9%). Just over 1 in 5 people in cared accommodation (22.3%) did not have difficulty with managing their bladder or bowel control. These people were more likely to be younger than people who always or sometimes needed help—16.1% of those who did not have difficulty were aged 0–64 compared with 7.1% of people who always or sometimes needed help.

Figure 4.10 displays the level of assistance needed with managing bladder or bowel control for people in households compared with people in residential settings. A large majority of people living in households (87.8%) had no difficulty with managing their own bladder or bowel control. In comparison, a large proportion of people in cared accommodation always or sometimes (74.0%) needed assistance, regardless of their age. This supports the notion that needing help to manage continence-related issues is a major factor contributing to the decision for older people to move to cared accommodation (Pearson et al. 2002a).



Note: See Appendix Tables A9 and A10 for the data in this figure.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 4.10: Proportion of people with disability by level of assistance needed with managing bladder or bowel control, residential status and age, 2009

Help needed to manage toileting

Needing help to manage toileting is different to needing help with managing bladder or bowel control. Toileting requires the physical and intellectual capacity to carry out the steps needed to use the toilet, including knowing where the toilet is, removing the necessary clothing, using the toilet appropriately and getting dressed again.

The profile of need for assistance with managing toileting differs depending on residential status. A large majority of the 3.8 million people with disability living in households have no difficulty with toileting (93.3%). Nevertheless, in 2009, 123,300 (3.3%) always or sometimes needed help with toileting—in comparison, in 2003, about 108,400 (3.0%) of people with disability living in households needed help with toileting. Just under 7,000 (0.2%) people in households did not use the toilet at all (see Table A11).

By contrast, in 2009, almost 3 in 4 people (110,500 or 70.0%) people in cared accommodation always or sometimes needed help with toileting, almost three-quarters of whom were female (77,300, or 69.9%). Almost all were aged 65 and over (102,700, or 93.0%) (see Table A12).

Use of continence or toileting aids

People aged 10 and over with severe incontinence living in households are more likely to use aids than people without severe incontinence—about 76.1% of people with severe incontinence indicated they used one or more type of aid or equipment, compared with

44.5% of people without severe incontinence (see Table A13). When asked to list the types of activities for which aids or equipment were used, the most common responses by people with severe incontinence were:

- managing incontinence (55.8%)
- managing health conditions (43.9%)
- showering or bathing (40.6%).

A person may require continence aids if they experience urge, stress or functional incontinence. In 2009, about 96,100 (2.7%) of people with disability aged 10 and over living in households used continence aids, irrespective of their level of incontinence. The majority were aged 65 and over (63.4%) and 3 in 4 were female (73.1%) (see Table 4.6). In 2003, 83,800 (2.4%) people with disability aged 10 and over living in households used continence aids—this was not significantly different to 2009.

More than 9 in 10 (91.8%, or 3.3 million) people in households with disability did not need any additional aids to manage continence; however, 216,100 (6.0%) people did need additional aids (besides continence aids), and 4,700 (0.1%) needed additional continence aids.

A substantially greater proportion of people living in cared accommodation with or without disability used continence aids (63.2%) than the household population (2.7%). This represents 99,700 people with disability of the 157,800 living in cared accommodation.

Table 4.6: People who use continence aids, by age, sex and residential status, 2009

	Households		Cared accommodation	
Age (years)	**Number**	**Per cent**	**Number**	**Per cent**
Males				
0–64	*10,187	*10.6	3,339	3.3
65+	15,617	16.3	25,078	25.2
All males	*25,804*	*26.9*	*28,417*	*28.5*
Females				
0–64	25,017	26.0	3,044	3.1
65+	45,282	47.1	68,224	68.4
All females	*70,299*	*73.1*	*71,268*	*71.5*
Persons				
0–64	35,204	36.6	6,383	6.4
65+	60,899	63.4	93,302	93.6
All persons	**96,103**	**100.0**	**99,686**	**100.0**

* Estimate has a relative standard error of 25-50% and should be used with caution.

Notes

1. Excludes children under 10 living in households.
2. Components may not add to total due to rounding.

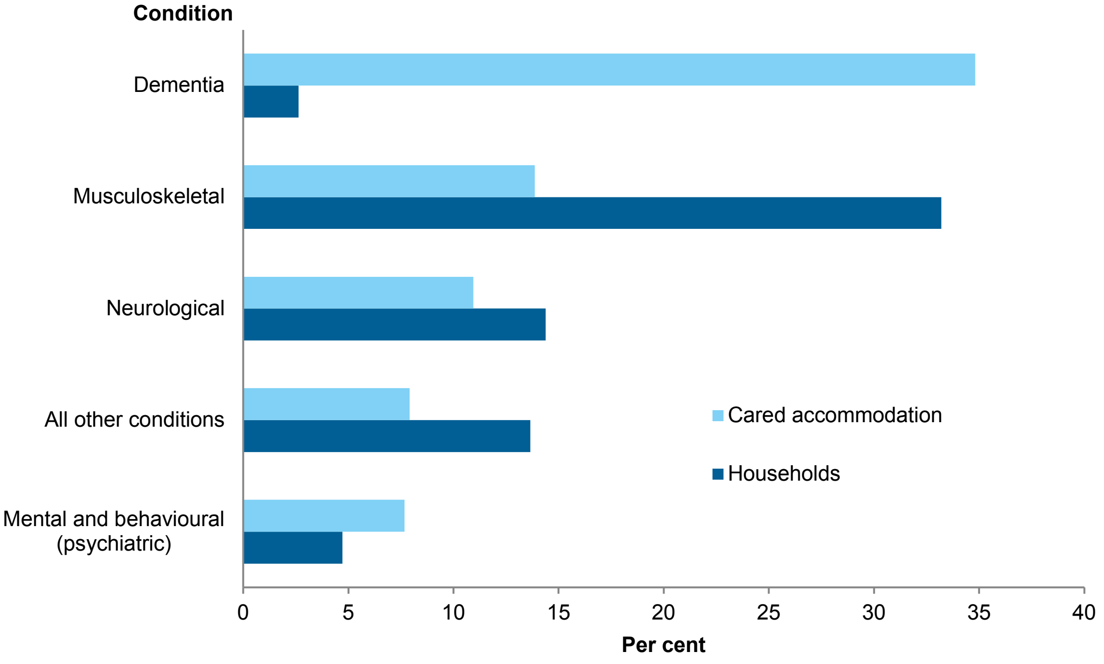
Source: AIHW analysis of the 2009 ABS SDAC CURF.

Toileting aids are used by people who have difficulties physically accessing and using the toilet. About 1 in 20 (185,300 or 5.1%) people living in households used toileting aids. A higher proportion of females (6.3%) used toileting aids than males (3.9%). More than 2 in 5 people (1,585,800 or 43.8%) did not use toileting aids, but used other aids to go the toilet (see Table A14).

Conditions associated with continence aid use

In the 2009 SDAC, people who reported having more than one health condition also indicated which was their main condition. The main conditions reported by people who used continence aids have been grouped according to the International statistical classification of diseases and related health problems, tenth revision, Australian modification (ICD-10-AM)(AIHW 2013) because some conditions had small sample sizes. See Incontinence in Australia: prevalence, experience and cost, 2009 (AIHW 2012a) for health conditions associated with people who have severe incontinence.

For people living in households and using continence aids, the most common main condition reported was 'musculoskeletal conditions' (including arthritis and related disorders, and back problems) (33.2%). It is possible that some of these people experienced symptoms of urge or stress incontinence, or had physical access issues and therefore experienced functional incontinence.



Note: See Appendix Table A15 for data in this figure and conditions included in each grouping.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

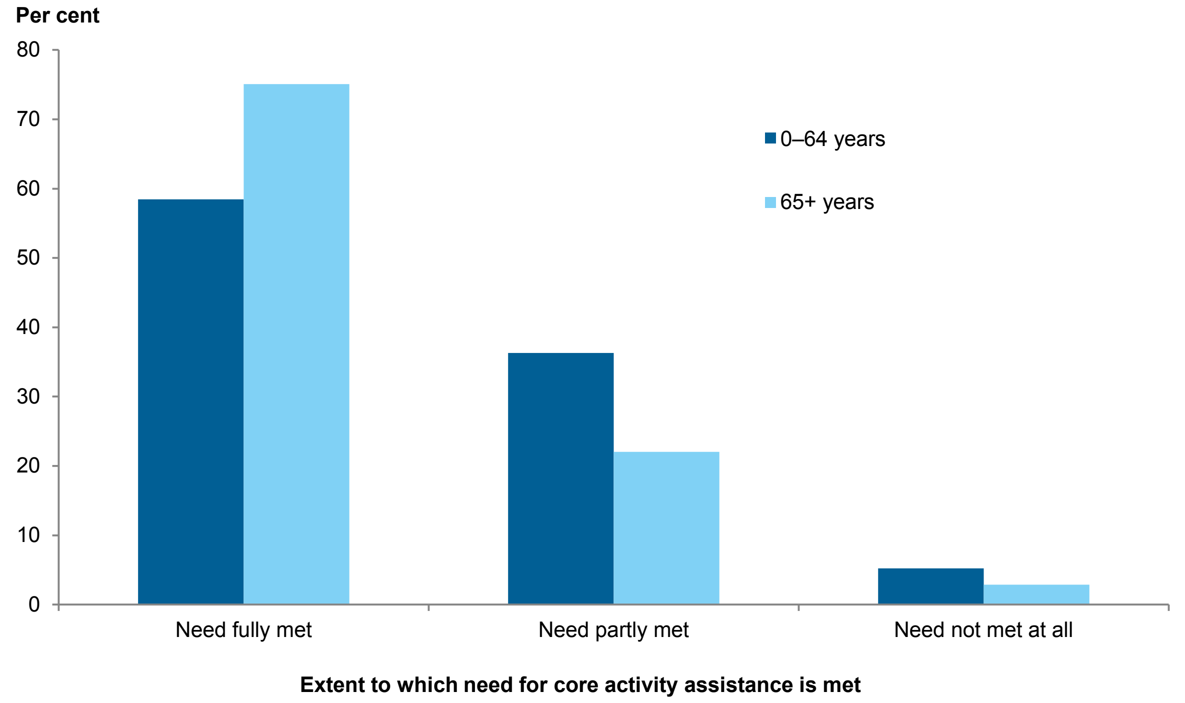
Figure 4.11: Proportion of people who use continence aids, by main grouped condition and residential status, 2009

An additional 1 in 7 (14.4%) people in households who used continence aids reported their main health condition was neurological (including Parkinson disease, multiple sclerosis and epilepsy)—again, this may result in stress, urge or functional incontinence.

Dementia (including Alzheimer disease) was reported by 1 in 3 people (34.8%) living in cared accommodation who used continence aids. In comparison, 2.6% of people living in households who used continence aids reported dementia (including Alzheimer disease) as their main condition. Other main conditions reported by people in cared accommodation who used continence aids included musculoskeletal (13.9%), neurological (10.9%) and stroke (9.6%).

Need for assistance and services received

In 2009, 2 in 3 people who needed assistance with managing their own bladder or bowel control (91,200 or 65.6%) reported that their need for assistance was fully met for core activities. Further, almost 1 in 3 (30.2%) had their need partly met. Close to 6,000 (4.2%) people reported that their need was not met at all for their core activities. A higher proportion of people aged 65 and over reported that their need for assistance was fully met than people aged 0–64 (75.1% versus 58.5%) (see Figure 4.12).



Notes

1. See Appendix Table A16 for data in this figure.
2. Estimates for 'Need not met at all' have relative standard errors of 25-50% and should be used with caution.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 4.12: Proportion of people living in households who needed assistance with managing their bladder or bowel control, by extent to which need for core activity assistance was met, 2009

Type of services received

People with disability can receive either formal or informal assistance. In the SDAC, informal assistance is defined as unpaid help or supervision provided by family, friends or neighbours to people with one or more disability. Formal assistance is help provided to people with disability by organisations, or individuals representing organisations (whether or not they are profit-making), or other persons (excluding family, friends or neighbours) who provide help on a regular paid basis.

In the 2009 SDAC, it is not possible to identify people who received assistance specifically with bladder or bowel control, or with toileting. However, people who received assistance more generally with self-care can be identified. In 2009, of those people who always or sometimes needed help with managing their bladder or bowel control, 28.1% received no assistance with self-care (see Table 4.7)—in comparison, 15.9% received no assistance with self-care in 2003 (AIHW 2006). This difference was not statistically significant. In 2009, a further 46.2% received informal assistance but not formal assistance with self-care, compared with 55.0% in 2003.

Table 4.7: People living in households and who need assistance with managing bladder or bowel control, by type of assistance received with self-care, by age, 2009

	0–64 years		65+ years		All persons	
	Number	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
None	21,443	27.0	17,657	29.6	39,100	28.1
Informal only	39,826	50.2	24,364	40.8	64,190	46.2
Formal only	7,771	9.8	*7,060	*11.8	14,831	10.7
Informal and formal	10,330	13.0	10,563	17.7	20,893	15.0
Total	**79,369**	**100.0**	**59,645**	**100.0**	**139,014**	**100.0**

* Estimate has a relative standard error of 25–50% and should be used with caution.

Note: Components may not add to total due to rounding.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

5 Carers who help manage incontinence

Caring for a person with disability is often described in both positive and negative terms—satisfying, burdensome, rewarding, stressful (Llewellyn et al. 2010). Some carers have an additional task of helping someone manage their bladder or bowel control, or toileting. The following analysis presents the experiences of primary carers who provide informal incontinence-related support compared with primary carers who do not provide incontinence-related support. Informal assistance is unpaid help or supervision provided to a person.

Characteristics of carers

Table 5.1 compares the characteristics of primary carers who helped manage incontinence with those who did not. According to the 2009 SDAC, there were 746,300 primary carers in Australia—9.8% of whom usually helped manage someone else's incontinence. Of the 72,900 primary carers who usually helped manage incontinence, 4 in 5 (81.2%) were female. In comparison, of the 673,500 primary carers who did not usually help manage incontinence, just under 2 in 3 (65.7%) were female.

More than half (55.1%) of the primary carers who helped manage someone else's incontinence were aged 40–64, 1 in 4 (24.6%) were aged 65 and over and 1 in 5 were aged 0–39 (20.4%). This age distribution was similar to that of primary carers who did not help manage someone else's incontinence.

Just over 1 in 10 (10.4%) primary carers living in major cities usually provided help with managing incontinence. In comparison, fewer than 1 in 10 (9.6%) primary carers living in inner regional areas and 6.1% of primary carers living in other areas usually helped manage incontinence. Irrespective of their country of birth, about 1 in 10 primary carers usually helped with managing incontinence (9.6% of Australia-born primary carers, 9.7% of primary carers born in main English-speaking countries and 10.6% of primary carers born in other countries).

Just over half (51.9%) of the primary carers who provided incontinence-related care received up to $450 each week in cash income and just over 1 in 4 (26.6%) received $451–$958 per week. A smaller proportion of these primary carers were higher income earners (earning $959 or more per week) than primary carers who did not provide incontinence-related assistance (9.6% versus 15.3%). This is likely to be related to the differences in the source of their cash income.

A greater proportion of primary carers who help manage someone else' incontinence reported their main source of cash income to be government pensions or allowances (62.7%) than primary carers who did not provide this kind of support (52.5%). The main type of pension or allowance received by those who provide incontinence-related support was the Mature Age Allowance/Wife Pension/Carer Payment/Widow Allowance/Partner Allowance (37.5% of those receiving a government pension or allowance). It is not possible to tell how many people received each specific payment from this category; however, this proportion was almost double that of primary carers who did not provide incontinence-related support (17.8%).

Table 5.1: Characteristics of primary carers, by whether assisted with managing incontinence, 2009

	Usually assists with managing incontinence			Does not usually assist with managing incontinence			Total primary carers	
	Number	Per cent (column)	Per cent (row)	Number	Per cent (column)	Per cent (row)	Number	Per cent (column)
Sex								
Male	13,729	18.8	5.6	230,676	34.3	94.4	244,406	32.7
Female	59,127	81.2	11.8	442,811	65.7	88.2	501,938	67.3
Age group (years)								
0–39	14,843	20.4	10.3	128,895	19.1	89.7	143,738	19.3
40–64	40,123	55.1	9.8	368,155	54.7	90.2	408,278	54.7
65–84	16,392	22.5	9.0	165,075	24.5	91.0	181,467	24.3
85+	**1,498	**2.1	**11.7	11,362	1.7	88.3	12,861	1.7
0–64	54,966	75.4	10.0	497,050	73.8	90.0	552,016	74.0
65+	17,890	24.6	9.2	176,438	26.2	90.8	194,328	26.0
Remoteness								
Major cities	50,566	69.4	10.4	437,357	64.9	89.6	487,923	65.4
Inner regional	18,094	24.8	9.6	171,254	25.4	90.4	189,348	25.4
Other areas	*4,196	*5.8	*6.1	64,876	9.6	93.9	69,072	9.3
Country of birth								
Australia	50,531	69.4	9.6	478,148	71.0	90.4	528,679	70.8
Main English-speaking country	7,927	10.9	9.7	73,797	11.0	90.3	81,724	10.9
Other	14,397	19.8	10.6	121,543	18.0	89.4	135,940	18.2
Weekly cash income								
$1–$450	37,823	51.9	10.4	326,913	48.5	89.6	364,735	48.9
$451–$958	19,368	26.6	8.9	197,308	29.3	91.1	216,676	29.0
$959 and above	*6,989	*9.6	*6.3	103,347	15.3	93.7	110,336	14.8
Not known	8,676	11.9	15.9	45,920	6.8	84.1	54,596	7.3
Main source of cash income								
Not applicable	**1,469	**2.0	**5.3	26,480	3.9	94.7	27,948	3.7
Employee income	17,879	24.5	7.9	208,033	30.9	92.1	225,911	30.3
Unincorporated business income	**1,170	**1.6	**4.7	23,472	3.5	95.3	24,643	3.3
Government pensions and allowances	45,683	62.7	11.4	353,418	52.5	88.6	399,100	53.5
Other income	5,763	7.9	8.9	58,814	8.7	91.1	64,576	8.7

(continued)

Table 5.1 (continued): Characteristics of primary carers, by whether assisted with managing incontinence, 2009

	Usually assists with managing incontinence			Does not usually assist with managing incontinence			Total primary carers	
	Number	Per cent (column)	Per cent (row)	Number	Per cent (column)	Per cent (row)	Number	Per cent (column)
Not known	**893	**1.2	**21.4	*3,272	*0.5	*78.6	*4,165	*0.6
Whether receives any government pensions, allowances or benefits								
Age Pension	9,754	13.4	6.8	134,191	19.9	93.2	143,945	19.3
Newstart, Sickness or Youth Allowance	**1,354	**1.9	**5.1	25,373	3.8	94.9	26,727	3.6
Mature Age Allowance, Wife Pension, Carer Payment, Widow Allowance or Partner Allowance	27,342	37.5	18.6	119,886	17.8	81.4	147,228	19.7
Service Pension (DVA)	**1,121	**1.5	**5.8	18,078	2.7	94.2	19,198	2.6
Disability Support Pension	*4,254	*5.8	*9.0	42,933	6.4	91.0	47,187	6.3
Special Benefit/ Don't know	–	–	–	*2,227	*0.3	*100.0	*2,227	*0.3
None of these	29,031	39.8	8.1	330,800	49.1	91.9	359,831	48.2
Persons	**72,856**	**100.0**	**9.8**	**673,488**	**100.0**	**90.2**	**746,344**	**100.0**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Notes

1. Components may not add to total due to rounding.
2. DVA denotes Department of Veteran Affairs.

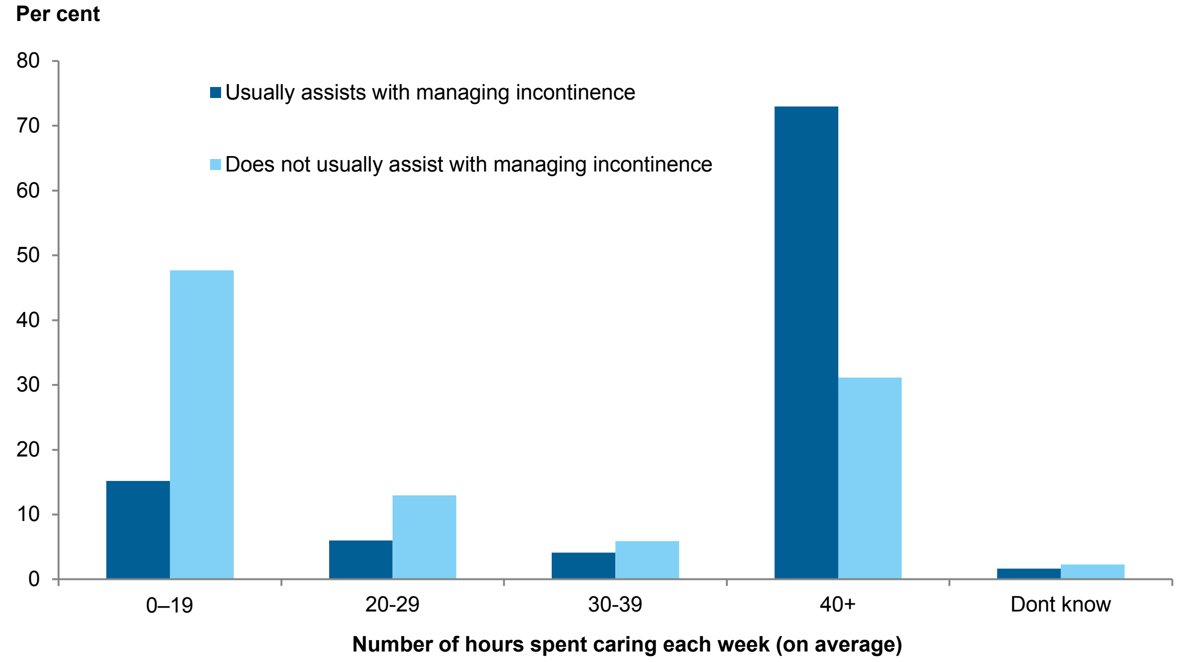
Source: AIHW analysis of the 2009 ABS SDAC CURF.

Effect of incontinence on the primary carer

As discussed previously, providing care for someone has been associated with both satisfaction and stress (Llewellyn et al. 2010). The nature of incontinence and the tasks required to help someone else manage their incontinence are likely to add to the feelings of stress and burden, but while incontinence may contribute to some of the burden on carers, it is not the sole source of negative effects on primary carers.

Level of care provided

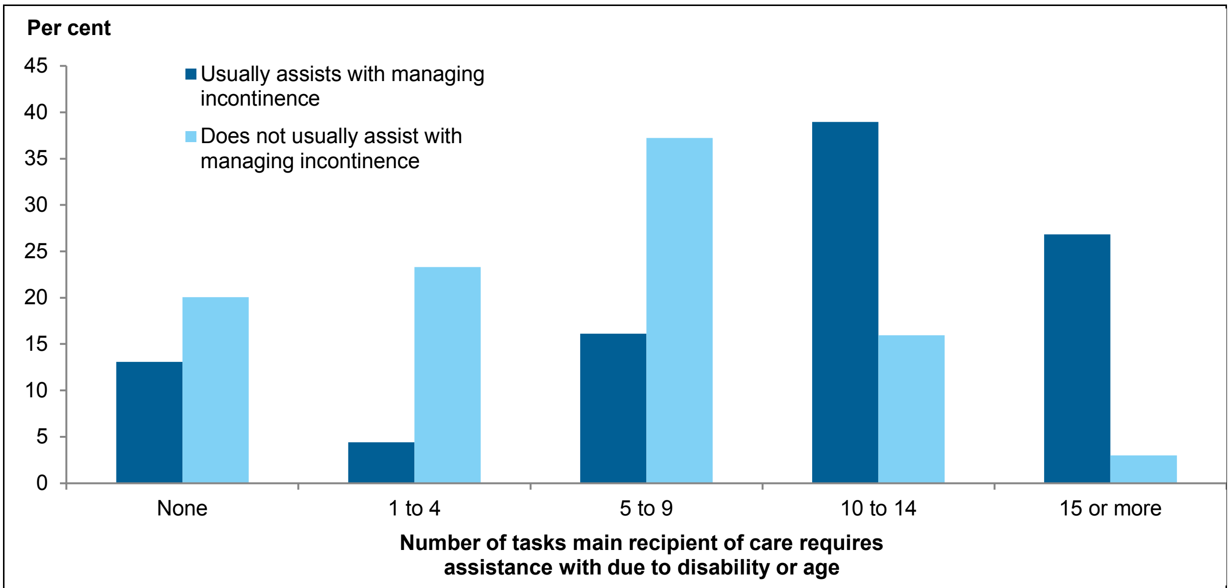
Primary carers who helped manage incontinence spent significantly more time providing care each week than primary carers who did not help manage incontinence. Just under 3 in 4 (73.0%) primary carers who provided incontinence-related assistance spent 40 or more hours caring each week, compared with almost 1 in 3 (31.1%) who did not provide this kind of assistance (see Figure 5.1). Primary carers who helped manage incontinence provided assistance with a greater number of tasks than primary carers who did not help manage incontinence (see Figure 5.2)—perhaps this is related to the greater number of hours primary carers who manage incontinence-related issues spend providing care.



Note: See Appendix Table A17 for data in this figure.

Source: AIHW analysis of the 2009 ABS SDAC CURF

Figure 5.1: Proportion of primary carers by grouped number of hours spent caring each week (on average) and whether primary carer usually assisted with managing incontinence, 2009



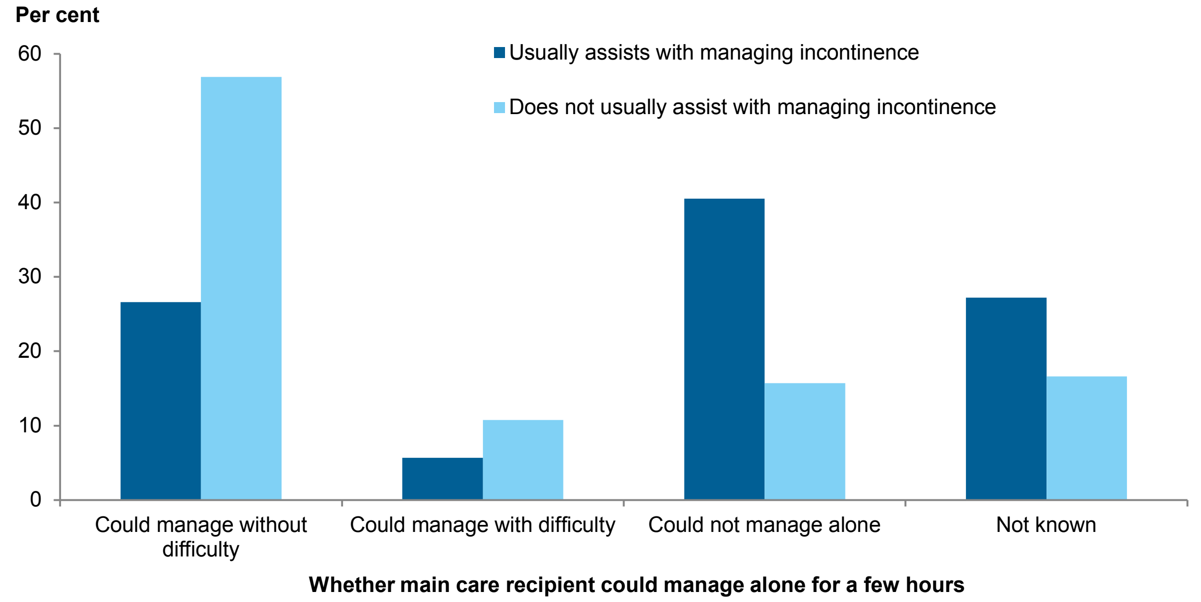
Notes

1. See Appendix Table A17 for the data in this figure.
2. 4.9% of responses by primary carers who did not help manage someone else' incontinence were 'not applicable'.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 5.2: Proportion of primary carers by number of tasks for which assistance is required and whether primary carer usually helped manage incontinence, 2009

The ability of a recipient of care to manage at home alone for a few hours is an important factor that can ease the burden felt by primary carers who live with their care recipient. A greater proportion of primary carers who helped manage someone else's incontinence reported that the main recipient of care could not manage alone for a few hours, than primary carers who did not provide incontinence-related care (40.5% versus 15.7%) (Figure 5.3).



Note: See Appendix Table A18 for the data in this figure.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 5.3: Proportion of primary carers by whether main recipient of care could care for themselves at home alone for a few hours and whether carer usually helped manage their incontinence, 2009

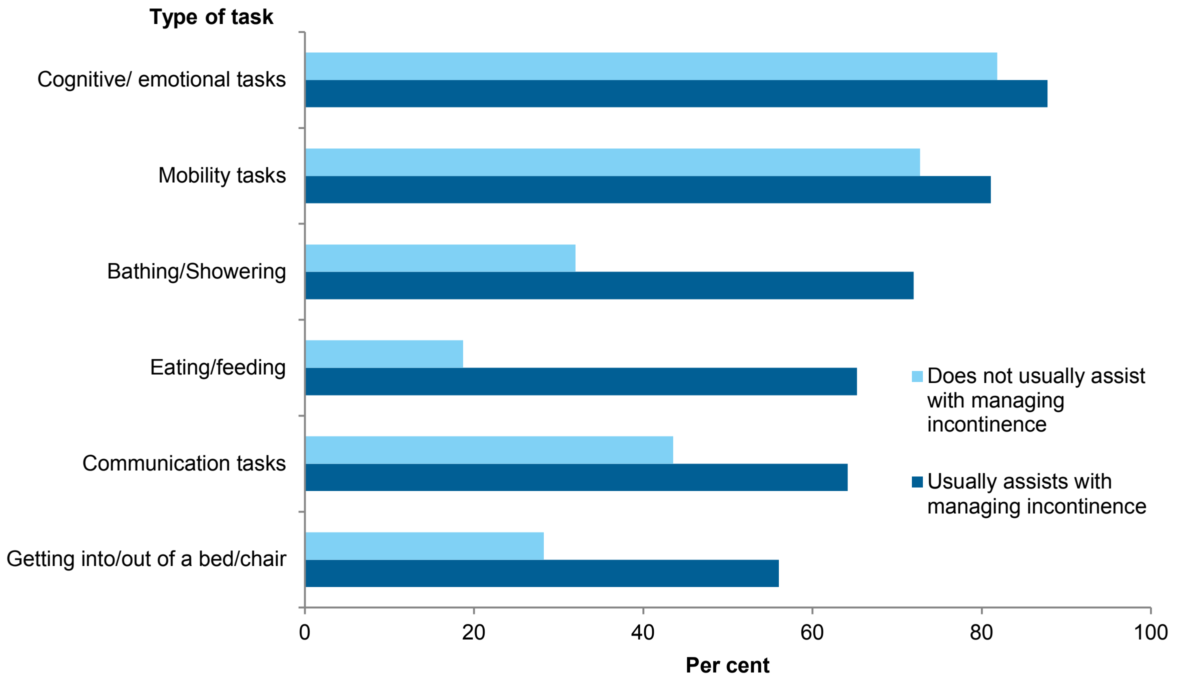
Type of care provided

People with incontinence experience different types of limitations than people without incontinence (see 'Other health issues for people with severe incontinence' in Chapter 4). Consequently, primary carers provide different types of help to care recipients, depending on whether or not they help with managing incontinence-related issues.

Three types of tasks where there were significant differences were (Figure 5.4):

- Eating or feeding: 65.3% of primary carers who helped manage incontinence-related issues also assisted with eating or feeding, compared with 18.7% of primary carers who did not help manage incontinence.
- Bathing or showering: 71.9% of primary carers who helped manage incontinence-related issues also assisted with bathing or showering, compared with 32.0% of primary carers who did not help manage incontinence.
- Getting into or out of a bed or chair: 56.0% of primary carers who helped manage incontinence-related issues also helped sufferers in and out of bed, compared with 28.3% of primary carers who did not help manage incontinence.

A high proportion of primary carers, whether or not they helped manage someone else's incontinence, assisted the recipient of care with cognitive or emotional tasks (87.8% and 81.8%, respectively). These findings reflect that people with severe incontinence usually have a severe or profound core activity limitation (see Figure 4.1 and Table A19).



Note: See Appendix Table A19 for the data in this figure.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 5.4: Proportion of primary carers by type of task they assist recipient of care with, and whether they also helped manage incontinence of recipient of care, 2009

Effect of caring role on participation

Labour force participation

The labour force participation rate of primary carers aged 15 to 64 who helped manage incontinence was lower than the rate for primary carers who did not assist with incontinence (44.3% versus 55.4%) (see Table A20). About 1 in 4 primary carers, whether or not they provided incontinence-related support, were employed part time (28.1% and 25.9%, respectively). People who helped manage someone else's incontinence were less likely to be employed full time (15.2%), than people who did not help manage incontinence (26.7%). Providing incontinence-related support may be one factor contributing to low labour force participation of primary carers; however, it is likely there are others, given the low labour force participation rate of other primary carers.

Social or community participation

In the 2009 SDAC, primary carers aged under 60 and primary carers without a disability were asked a question about whether they had participated in social or community activities without the recipient of care in the past 12 months. There were many primary carers who were not asked this question—50.0% of those who provided incontinence-related support and 57.7% of those who did not. Of those who were asked, about the same proportion of primary carers who helped with incontinence participated in social or community activities in the previous 12 months (71.1%) as primary carers who did not help with incontinence (69.5%) (see Table A21).

Effect of caring role on carers' financial situation

Financial stress for primary carers can comprise a double burden of decreased income and increased expenses. Providing care for another person may affect the primary carer's availability to participate in the workforce and, hence, their potential income. Carers may also have additional expenses (such as treatment, equipment or medication costs) for the person they care for.

According to the 2009 SDAC, a greater proportion of primary carers who provided incontinence-related help reported that their financial situation changed due to their caring role (64.5% compared with 46.5%) (a small proportion reported an increase in income). This included:

- 27.7% of primary carers who helped manage someone else's incontinence reporting a decrease in income, compared with 20.7% of primary carers who did not help manage someone else's incontinence
- 34.2% of primary carers who helped manage someone else's incontinence reporting extra expenses, compared with 22.8% of primary carers who did not help manage someone else's incontinence (see Table A21).

Effect of caring role on carer relationships, health and wellbeing

Relationships

About 1 in 3 primary carers living in households (31.9%) reported that the caring role brought their relationship with their main recipient of care closer, regardless of whether they provided incontinence-related support or not (see Table 5.2). A greater proportion of primary carers who provided incontinence-related support reported their relationship with the main recipient of care was strained due to the caring role—that is, 1 in 4 (23.8%) primary carers who provided incontinence-related support compared with 1 in 6 (16.2%) primary carers who did not provide incontinence-related support.

About 1 in 8 primary carers who provided incontinence-related support (12.7%) and 1 in 7 who did not provide incontinence-related support (15.2%) reported that the caring role brought them closer together with their spouse or partner (see Table 5.2) (primary carers whose main recipient of care was their spouse were not asked this question). Primary carers who provided help with managing someone else's incontinence were about twice as likely to have a strained relationship with their spouse or partner (13.6%) or not have a spouse or partner (11.3%) compared with carers who did not provide incontinence-related support (5.8% and 6.3%, respectively).

More than 1 in 3 (35.2%) primary carers who helped manage someone else's incontinence reported their friendships remained unchanged, and just over 1 in 3 (38.7%) had lost or were losing touch with their existing friends. Fewer primary carers who did not provide incontinence-related support were affected in these ways: more than 1 in 2 (56.9%) reported that their friendships remained unchanged, and 1 in 5 (20.3%) reported they had lost or were losing touch with existing friends.

Table 5.2: Main effect of caring role on primary carer's relationships, by whether usually assisted with managing someone else's incontinence, 2009

	Usually assists with managing incontinence		Does not usually assist with managing incontinence		Persons
	Number	Per cent	Number	Per cent	Number
Main effect on relationship with main recipient of care					
Relationship unaffected	24,457	33.6	283,259	42.1	307,716
Brought closer together	24,052	33.0	213,756	31.7	237,808
Relationship strained	17,324	23.8	109,323	16.2	126,647
Not stated	7,023	9.6	67,149	10.0	74,172
Main effect on relationship with spouse/partner					
Not applicable	22,238	30.5	281,901	41.9	304,139
Relationship unaffected	13,078	17.9	112,733	16.7	125,811
Brought closer together	9,223	12.7	102,702	15.2	111,925
Lack time alone together	*3,220	*4.4	22,030	3.3	25,249
Relationship strained	9,891	13.6	39,374	5.8	49,265
Has no spouse or partner	8,202	11.3	42,379	6.3	50,581
Not stated	7,005	9.6	72,369	10.7	79,373
Main effect on relationship with co-resident family members					
Has no other co-resident family members	20,908	28.7	238,453	35.4	259,360
Relationships unaffected	16,004	22.0	208,255	30.9	224,260
Less time to spend with them	16,017	22.0	68,820	10.2	84,837
Brought closer together	*5,191	*7.1	38,186	5.7	43,377
Relationships strained	*6,934	*9.5	40,613	6.0	47,547
Relationships affected in another way	**901	**1.2	7,893	1.2	8,794
Not stated	6,901	9.5	71,267	10.6	78,169
Main effect on primary carer's friendships					
Friendships unaffected	25,646	35.2	383,276	56.9	408,922
Circle of friends has increased	*1,375	*1.9	15,566	2.3	16,941
Circle of friends has changed	10,487	14.4	70,100	10.4	80,587
Lost or losing touch with existing friends	28,212	38.7	136,601	20.3	164,813
Not stated	7,137	9.8	67,944	10.1	75,080
Persons	**72,856**	**100.0**	**673,488**	**100.0**	**746,344**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Notes

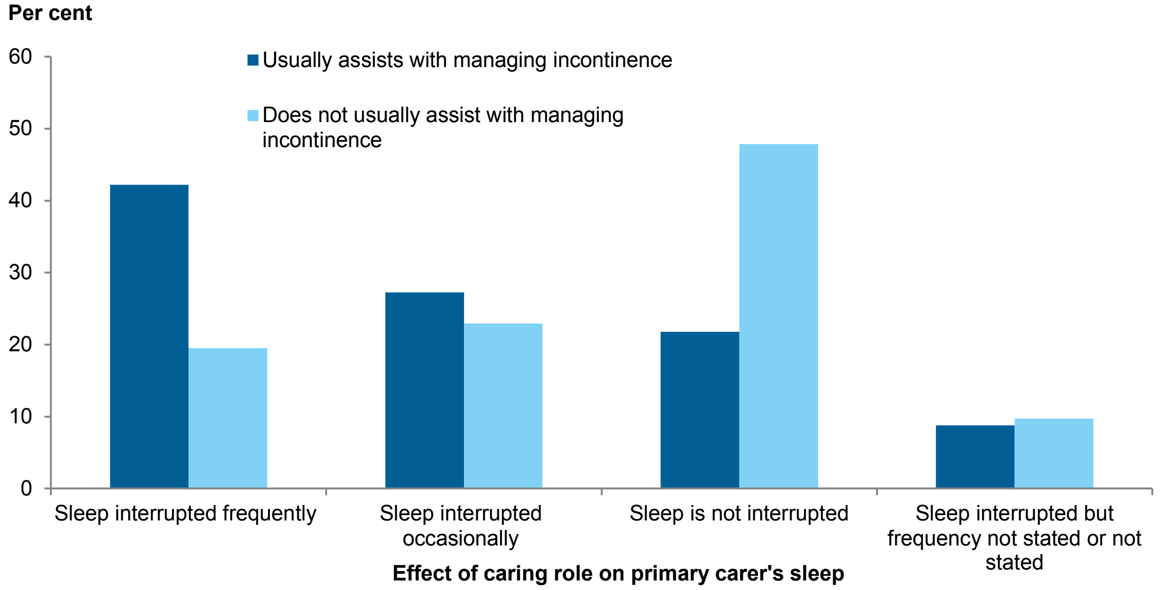
1. Primary carers applicable for the question 'Effect on relationship with spouse/partner' include only those whose main recipient of care is not their spouse or partner.
2. Components may not add to total due to rounding.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Health and wellbeing

Sleep

Many primary carers who provided incontinence-related support reported that their sleep was interrupted frequently (42.2%); 1 in 3 primary carers (33.5%) reported that this interfered with their daily activities. In comparison, 19.5% of primary carers who did not provide incontinence-related support reported their sleep was interrupted frequently, including 1 in 7 (15.0%) primary carers who reported that it interfered with their normal daily activities (see Figure 5.5).



Note: See Appendix Table A22 for the data contained in this figure.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 5.5: Proportion of primary carers by effect of caring role on primary carer's sleep and whether usually assisted with managing incontinence, 2009

The association between poorer sleep outcomes for primary carers who provide incontinence-related support may be a direct cause of needing to provide incontinence-related support throughout the night. It may also be related to the higher support needs of people with incontinence. Either way, the effect of interrupted sleep is likely to have an influence on carer health and wellbeing.

Emotional wellbeing

In the 2009 SDAC, the task of helping someone with their incontinence was associated with poorer emotional wellbeing (see Table 5.3). Almost 1 in 5 primary carers who usually helped manage incontinence had been diagnosed with a stress-related illness (18.7%) and nearly 1 in 2 felt weary or lacked energy (45.0%). In comparison, 1 in 10 primary carers who did not usually help manage incontinence had been diagnosed with a stress-related illness (10.1%) and 1 in 3 felt weary or lacked energy (30.2%).

Table 5.3: Main effect of caring role on primary carer emotional wellbeing, by whether usually assisted with managing someone else' incontinence, 2009

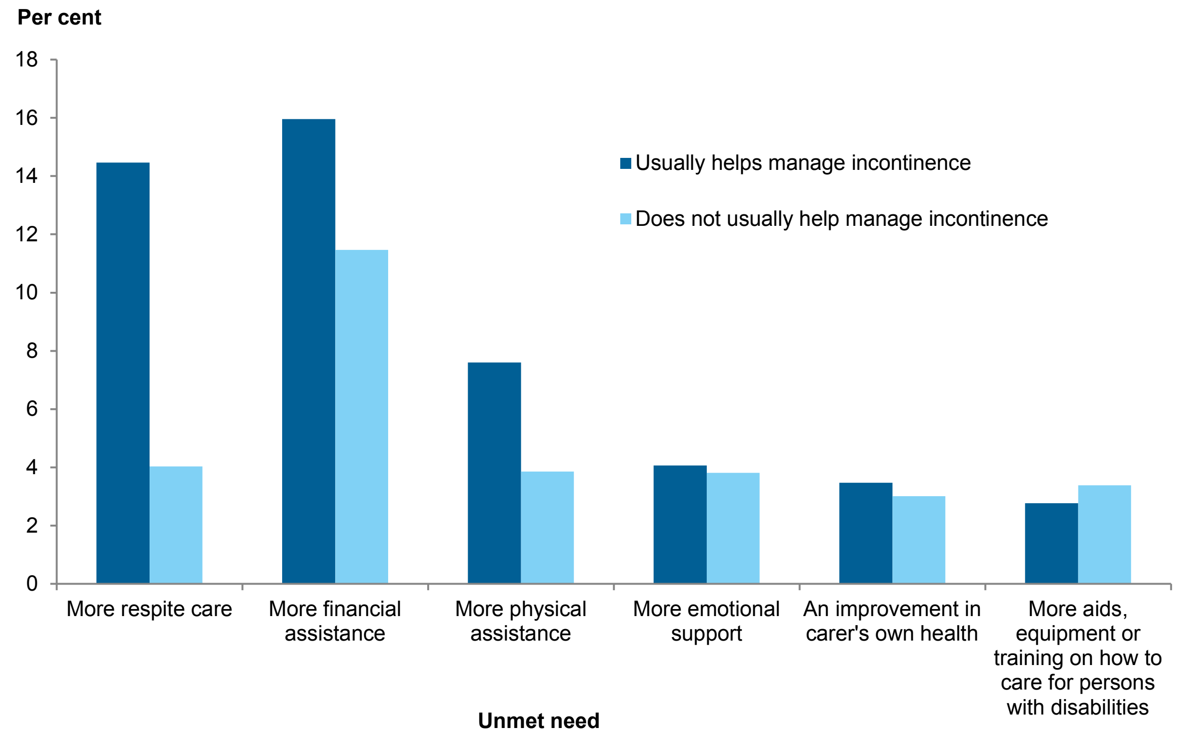
	Usually assists with managing incontinence		Does not usually assist with managing incontinence		Persons
	Number	Per cent	Number	Per cent	Number
Diagnosed with stress-related illness					
Has been diagnosed	13,645	18.7	67,925	10.1	81,570
Has not been diagnosed	52,555	72.1	535,739	79.5	588,294
Not stated	6,656	9.1	69,823	10.4	76,480
Change in physical or emotional wellbeing					
Physical or emotional well-being has changed	36,148	49.6	204,424	30.4	240,572
Physical or emotional well-being has not changed	30,052	41.2	399,241	59.3	429,292
Not stated	6,656	9.1	69,823	10.4	76,480
Feels weary or lacks energy					
Feels weary or lacks energy	32,761	45.0	203,183	30.2	235,944
Does not feel weary or lack energy	33,439	45.9	400,481	59.5	433,920
Not stated	6,656	9.1	69,823	10.4	76,480
Feels worried or depressed					
Frequently feels worried or depressed	28,790	39.5	193,580	28.7	222,370
Does not frequently feel worried or depressed	37,409	51.3	410,084	60.9	447,494
Not stated	6,656	9.1	69,823	10.4	76,480
Feelings of satisfaction					
Feels satisfied due to caring role	13,655	18.7	149,567	22.2	163,222
Does not feel satisfied due to caring role	52,545	72.1	454,097	67.4	506,642
Not stated	6,656	9.1	69,823	10.4	76,480
Persons	**72,856**	**100.0**	**673,488**	**100.0**	**746,344**

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Nevertheless, providing this type of support did not affect satisfaction due to their caring role—about 1 in 5 primary carers felt satisfied due to their caring role regardless of whether or not they provided incontinence-related support (18.7% and 22.2%, respectively).

Unmet need

The main areas of unmet need for primary carers who helped manage incontinence were financial assistance and respite care—reported by about 1 in 6 people each (16.0% and 14.5%, respectively). While financial assistance was also the most common unmet need for primary carers who did not help manage incontinence (11.5%), respite care was a much less common unmet need (4.0%) (see Figure 5.6). No additional support was required by 36.1% of primary carers who helped manage incontinence and 53.2% of primary carers who did not provide this type of help (see Table A23).



Notes

1. See Appendix Table A23 for the data contained in this figure.
2. Just under 16.0% of primary carers, regardless of whether or not they provided incontinence-related support, did not answer the question about main unmet need.
3. 1.5% of primary carers who do not provide incontinence-related support reported ‘none of the above’ to the question about main unmet need.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Figure 5.6: Proportion of primary carers by main sources of unmet need and whether usually helped manage incontinence, 2009.

6 Expenditure

There are direct, indirect and intangible costs associated with incontinence:

- Direct costs are those that can be directly associated with health care, such as residential aged care costs, hospital and medical costs, pharmaceuticals and out-of-pocket expenses.
- Indirect costs are incurred due to reduced productivity of an individual or their carer or family members, due to incontinence (for example, time off work). Other indirect costs may include additional laundry and clothing costs.
- Intangible costs are difficult or sometimes impossible to measure, but nonetheless are important; these include anxiety or burden due to incontinence (Elliott & Payne 2005).

This report provides expenditure data for aged care services that were not available at the time of the previous bulletin (AIHW 2012a), as well as updated incontinence expenditure for 2008–09, including residential aged care costs. Time series comparisons before the 2008–09 financial year should be treated with caution due to a new data source for residential aged care costs and revised methodology. For the purposes of this report, the term 'expenditure' includes funding.

Expenditure estimates can vary considerably depending on the costs included or excluded from the analysis. This chapter looks at the estimated costs associated with incontinence from a health-care system perspective for the 2008–09 financial year. Some incontinence-related costs for 2009–10 are also presented. Expenditure includes the combined costs for urinary and fecal incontinence, as for most expenditure data sources it is not possible to separate the two. This chapter also presents a brief discussion on the burden of incontinence—the quantification of the effect of incontinence on people's lives.

Expenditure on incontinence is described where it can be identified. The identification of incontinence-related personal costs can be difficult—despite this, it is important to note that these personal costs may place considerable burden on individuals with incontinence and their families. For instance, primary carers assisting with someone else's incontinence were much more likely to experience frequent sleep interruptions, and to have an unmet need for respite care, than other primary carers (see 'Effects of caring role on carer relationships, health and wellbeing' in Chapter 5).

Also, 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. These limitations may lead to an underestimation of actual incontinence expenditure.

Estimated expenditure

In 2008–09, the estimated total expenditure on incontinence was $1.6 billion. A majority (82.8%) was for residential aged care. The costs in various areas of the health and residential aged care sector are detailed in Table 6.1 (for an alternative estimate of the economic impact of incontinence see Box 6.1).

Table 6.1: Health and residential aged care expenditures for incontinence, 2008–09

	Cost ($ million)	Per cent
Residential aged care[(a)]	1,302.6	82.8
Hospital expenditure	145.5	9.2
Stoma aids	67.6	4.3
Continence aids	31.6	2.0
Out-of-hospital medical services[(b)]	17.7	1.1
Other health professionals and services	3.8	0.2
Pharmaceuticals[(b)(c)]	3.8	0.2
Total	**1,572.6**	**100.0**

(a) Residential aged care expenditure is derived from analysis of the 2008–09 Aged Care Funding Instrument and the 2008–09 Resident Classification Scale.

(b) 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.

(c) Pharmaceuticals expenditure for 2008–09 was reported as $3.1 million in AIHW (2012c). This figure has since been revised due to an issue with the allocation of costs for private prescriptions.

Notes

1. Information represents direct costs only – for a discussion of indirect costs, see the introduction to this chapter.
2. 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.

Box 6.1: Alternative estimation of the economic impact of incontinence

In 2011, Deloitte Access Economics (DAE) released its report, *The economic impact of incontinence in Australia* (DAE 2011), providing details on the direct, indirect and intangible costs associated with incontinence. It estimated a total financial cost of incontinence (excluding burden of disease) in 2010 of $42.9 billion, or $9,014 per person with incontinence. These figures included direct health-care system costs ($270.8 million), residential aged care costs ($1.6 billion), indirect costs including productivity losses of those with incontinence ($34.1 billion) and their unpaid carers ($2.7 billion), other indirect costs such as aids ($321 million), and deadweight losses (costs due to administering taxation and transfer system and distortions to behaviour ($3.8 billion). When including the cost of burden of disease, the cost of incontinence increased to $66.7 billion.

The DAE estimates are different to the estimates in this report for two reasons:

- The hospital cost data in the DAE report were derived by inflating the figures in the AIHW 2006 report to 2010. Hospital cost estimates in this report are derived from the latest available data in the AIHW disease expenditure database.
- DAE includes substantial indirect and intangible costs—this report includes only direct health-care system costs, unless otherwise stated.

Residential aged care

Incontinence is closely associated with ageing; therefore, many people with incontinence are in residential aged care facilities. The tasks involved in caring for people with incontinence in these facilities are intensive and time consuming, and hence costly. In comparison, although providing care for someone in the home environment is likely to be just as intensive, the time taken to provide this care is not paid time, so the costs are difficult to measure.

The costs of incontinence in residential aged care for both 2008–09 and 2009–10 are derived from the Aged Care Funding Instrument (ACFI). The ACFI was introduced on 20 March 2008, replacing the Resident Classification Scale (RCS), for allocating Australian Government subsidies to residential aged care providers. The ACFI is comprised of three components of residential care subsidy: activities of daily living (ADL), behaviour supplement and complex health-care supplement (for more details on the ACFI see <http://www.health.gov.au/acfi>). Toileting and continence are included in the ADL component of the ACFI (questions 4 and 5). In the ACFI, the question about toileting relates to the person's usual day-to-day care needs for using the toilet (setting up to use the toilet) and toilet completion (the ability to appropriately manage the toileting activity) (DoHA 2009). The person is rated on the level of toileting assistance they require; independent, supervision required, or physical assistance required. The question about continence relates to the person's usual assessed needs regarding urine and fecal continence. To complete the check list a Continence Record assessment is required, including a consecutive 3-day urinary record and a consecutive 7-day bowel record. A urine assessment is not required if the resident is continent or uses a urinary catheter. A bowel assessment is not required if the resident is continent, including if they have an ostomy or self-manages continence devices. Both the urine and fecal assessment includes recording the frequency of incontinence or leakage episodes.

Three residential aged care population groups were considered: people who only needed assistance with toileting, people who only needed assistance with managing continence, and people who needed assistance with both toileting and continence. The cost of incontinence in residential aged care was calculated by measuring the current level of basic subsidy funding for ADL using questions 1 to 5, including the costs of assisting residents with toileting and continence. Then, the level of basic funding that would be paid if the residents did not have any problems with toileting and continence was calculated, and subtracted from the original total current level of basic subsidy funding for ADLs. This difference represents the estimated cost of incontinence in the residential aged care sector. The costs of ongoing catheter care (excluding temporary catheters), the management of ongoing stoma care (excluding temporary stomas) and the administration of suppositories or enemas at least weekly were not included in residential aged care costs.

The population included in the costs for residential aged care were residents who had valid ACFI assessments during the 2008–09 financial year. This population was assumed to be representative of the population in residential aged care for the whole financial year. Some residents who were assessed using the RCS before March 2008 did not have an ACFI assessment in 2008–09. For those residents without an ACFI assessment that covered the full financial year, the level of subsidy was calculated using RCS appraisals for the months covered by the RCS and the ACFI appraisals for the months covered by the ACFI.

In 2008–09, the total residential aged care government subsidy specifically for incontinence was $1.3 billion—just under 30% of the total residential aged care government subsidy of $4.6 billion. Of the total expenditure on continence management and assistance with toileting in residential aged care, more than 71.8% was allocated to females and 95.5% was for people aged 65 and over (Table 6.2).

Table 6.2: Amount of residential aged care funding attributed to assistance with toileting and continence management ($million), by age and sex, 2008–09

	Needed assistance with continence		Needed assistance with toileting		Needed assistance with both continence and toileting		Total residential aged care funding on incontinence	
Age group (years)	**Cost**	**Per cent**	**Cost**	**Per cent**	**Cost**	**Per cent**	**Cost**	**Per cent**
Male								
0–64	1.4	2.8	1.1	3.7	26.9	2.2	29.4	2.2
65+	12.0	23.5	10.0	34.1	317.2	25.9	339.2	26.0
Total male	*13.4*	*26.3*	*11.1*	*37.7*	*344.0*	*28.1*	*368.6*	*28.2*
Female								
0–64	1.1	2.1	0.8	2.7	27.7	2.3	29.6	2.3
65+	36.6	71.7	17.5	59.6	852.8	69.6	906.9	69.5
Total female	*37.6*	*73.7*	*18.3*	*62.3*	*880.5*	*71.9*	*936.5*	*71.8*
Persons								
0–64	2.5	4.8	1.9	6.4	54.6	4.5	58.9	4.5
65+	48.6	95.2	27.5	93.6	1,170.0	95.5	1,246.1	95.5
All persons	**51.1**	**100.0**	**29.4**	**100.0**	**1,224.6**	**100.0**	**1,305.0**	**100.0**
Proportion of total residential aged care expenditure		**3.9**		**2.3**		**93.8**		**100.0**

Note: Components may not add to total due to rounding.

Source: AIHW analysis of DoHA ACFI and RCS.

The majority of expenditure on incontinence in residential aged care was for people who needed assistance with both continence and toileting (93.8%). The residential aged care government subsidy for incontinence in 2009–10 is discussed in Box 6.2.

Box 6.2: Incontinence costs in residential aged care for 2009–10

The financial year 2009–10 provides the first available complete year of government subsidy estimates for incontinence in residential aged care using the ACFI.

In 2009–10, the Australian government subsidy on incontinence was just under 30% of the total residential aged care subsidy—$1.3 billion of $4.8 billion. Of this expenditure, a majority was for people who required assistance with both toileting and continence management (94.8%). Almost three-quarters of the funding was for females (71.4%) and almost all was for people aged 65 and over (95.4%).

Comparisons between 2008–09 and 2009–10 residential aged care expenditure are limited because not all residents were assessed using the ACFI in the 2008–09 financial year. For this reason, 2008–09 costs are estimated from the ACFI and RCS appraisals, while 2009–10 costs are estimated solely from the ACFI appraisals.

Hospital expenditure

Measuring expenditure on incontinence in hospitals poses challenges for the identification and recording of costs. These include 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 this, and to challenges in measuring incontinence costs in other settings, the then Department of Health and Aged Care funded a project in 2005 to develop a framework for the economic and cost evaluation of continence conditions. The resulting report (Moore et al. 2006) showed that the coding for incontinence as a principal diagnosis on hospital morbidity records was inadequate. But even if it were adequate, most of the expenditure in hospital that was due to incontinence was for patients whose principal diagnosis was not incontinence.

The technique used to estimate expenditure on admitted patient hospital services considered three components 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 AIHW disease expenditure database contains estimates of expenditure by disease category, age group and sex for admitted patient hospital services, out-of-hospital medical services, prescription pharmaceuticals and other health services (see the data quality statement at <http://bit.ly/Z8qATx>). The database combines information from various databases, including the National Hospitals Morbidity Database (NHMD). The NHMD is a compilation of electronic summary separation records from admitted-patient morbidity data collections in Australian hospitals (AIHW 2012d). Expenditure on incontinence for patients whose main diagnosis was incontinence can be directly retrieved from the NHMD in the disease expenditure database. Estimation of expenditure for long- and short-stay admitted patients comes from the disease expenditure database, and uses numerous data sources.

For 2008–09, the NHMD recorded 7,957 patients diagnosed with incontinence who stayed in hospital for more than 3 months. On average, the cost of these patients' incontinence is estimated to be $43 per day in hospitals (derived from Moore et al. 2006, 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). The 2008–09 annual incontinence cost for long-stay hospital patients who always or sometimes needed help with bladder/bowel control was $51.3 million (Table 6.3).

Using a similar technique, expenditure can be estimated for patients in hospital for less than 3 months who had a diagnosis of incontinence additional to their main diagnosis. Applying a cost of $43 per day to the length of stay for these patients as well, the estimate of expenditure due to incontinence was $47.2 million. This figure is expected to be underestimated because incontinence as an additional diagnosis is often not recorded in the NHMD when it should be.

Table 6.3: Hospital incontinence-related expenditure, by age and sex (2008–09)

	Patients with an additional diagnosis of incontinence							
	Long-stay admitted patients		Short-stay admitted patients		Patients with principal diagnosis of incontinence		Total hospital expenditure	
Age (years)	**$million**	**Per cent**	**$million**	**Per cent**	**$million**	**Per cent**	**$million**	**Per cent**
Male								
0–64	19.4	37.9	3.2	6.8	2.2	4.6	24.8	17.1
65+	9.9	19.3	17.6	37.4	3.9	8.3	31.5	21.6
Total male	*29.4*	*57.2*	*20.9*	*44.2*	*6.1*	*12.9*	*56.3*	*38.7*
Female								
0–64	10.2	19.9	3.7	7.9	27.6	58.8	41.6	28.6
65+	11.7	22.8	22.6	47.9	13.3	28.2	47.6	32.7
Total female	*21.9*	*42.8*	*26.3*	*55.8*	*40.9*	*87.1*	*89.2*	*61.3*
Persons								
0–64	29.7	57.8	7.0	14.7	29.8	63.5	66.4	45.7
65+	21.6	42.2	40.2	85.3	17.2	36.5	79.0	54.3
Total persons	**51.3**	**100.0**	**47.2**	**100.0**	**47.0**	**100.0**	**145.5**	**100.0**
Proportion of total hospital expenditure		**35.3**		**32.4**		**32.3**		**100.0**

Notes

1. Long stay is defined as being in hospital for longer than 90 days.
2. Short stay is defined as being in hospital for 90 days or less.

Source: AIHW disease expenditure database.

Expenditure in hospitals for patients where the principal diagnosis was incontinence was $47.0 million in 2008–09, most of which was for females (87.1%). Total hospital expenditure for incontinence in 2008–09 was estimated at $145.5 million (Table 6.1), up from $110.5 million in 2003 (2008–09 prices). Just over half the hospital costs for incontinence were for people aged 65 and over (54.3%).

Out-of-hospital medical services

Another area of expenditure is the cost of accessing general practitioners (GPs) and specialists about incontinence. Specialists who may be involved in treating incontinence include urologists, gynaecologists, urogynaecologists and colorectal surgeons.

Total expenditure for out-of-hospital medical services was estimated at $17.7 million in 2008–09 (Table 6.4), down from $18.1 million in 2003 (2008–09 prices). In 2008–09, specialist attendances and unreferred 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 radiology. It is estimated that there were around 50,000 specialist attendances and more than 92,000 unreferred GP attendances for urinary incontinence nationally in 2008–09, compared with 30,000 and 94,000 attendances in 2003, respectively. Just over four-fifths of the out-of-hospital costs for incontinence were for females (84.0%) (Table 6.4).

Table 6.4: Out-of-hospital medical services[(a)] incontinence-related expenditure, by age and sex, 2008–09

	Unreferred GP		Imaging and pathology		Specialist		Other MBS medical services[(b)]		Total out-of-hospital costs	
Age (years)	**$million**	**Per cent**	**$million**	**Per cent**	**$million**	**Per cent**	**$million**	**Per cent**	**$million**	**Per cent**
Males										
0–64	0.5	10.6	0.3	7.3	0.5	8.4	0.1	2.8	1.4	7.9
65+	0.5	10.1	0.5	11.7	0.3	5.1	0.2	5.7	1.4	8.1
Total males	*1.1*	*20.7*	*0.8*	*19.0*	*0.8*	*13.6*	*0.3*	*8.5*	*2.8*	*16.0*
Females										
0–64	2.0	40.2	2.1	51.7	3.1	55.3	2.1	68.0	9.2	52.3
65+	2.0	39.0	1.2	29.3	1.7	31.1	0.7	23.4	5.6	31.7
Total females	*4.0*	*79.3*	*3.2*	*81.0*	*4.8*	*86.4*	*2.8*	*91.5*	*14.8*	*84.0*
Persons										
0–64	2.6	50.9	2.3	59.0	3.6	63.7	2.1	70.9	10.6	60.2
65+	2.5	49.1	1.6	41.0	2.0	36.3	0.9	29.1	7.0	39.8
Total persons	**5.1**	**100.0**	**4.0**	**100.0**	**5.6**	**100.0**	**3.0**	**100.0**	**17.7**	**100.0**
Proportion of total costs		**28.8**		**22.5**		**31.7**		**17.1**		**100.0**

(a) Out-of-hospital medical services expenditure is reliant on sample survey data that can be 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 radiology.

Note: The estimates in this section are derived using a combination of Bettering the Evaluation and Care of Health (BEACH) survey and Medical Benefits Schedule 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

Pharmaceuticals are used for the treatment of overactive bladder symptoms, stress urinary incontinence and incontinence due to urinary retention and overflow (Andersson et al. 2009). The following estimates include both Australian government and consumer out-of-pocket costs.

About 201,000 prescription items were prescribed for incontinence in 2008–09— 2.2 pharmaceuticals per GP attendance. Total expenditure on prescription pharmaceuticals in 2008–09 was estimated at $3.8 million. Females spent almost 3 times more on pharmaceuticals for incontinence than males ($2.8 million compared with $1.0 million). People aged 65 and over spent about 1.5 times more on pharmaceuticals than those under 65 ($2.3 million compared with $1.5 million) (see Table 6.5).

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 drug categories prescribed, and both were exclusively for urinary incontinence. Psychoanaleptics (9.7%) were the next most common, and were prescribed largely for urinary incontinence (92%) (Figure 6.1).

Table 6.5: Expenditure on pharmaceuticals for incontinence, by age and sex, 2008-09

Age (years)	$ million	Per cent
Male		
0–64	0.3	6.7
65+	0.7	18.7
Total male	*1.0*	*25.4*
Female		
0–64	1.3	33.5
65+	1.6	41.0
Total female	*2.8*	*74.6*
Persons		
0–64	1.5	40.3
65+	2.3	59.7
Total persons	**3.8**(a)	**100.0**

Note: Components may not add to total due to rounding.

(a) Note that in the bulletin released in December 2012, *Incontinence in Australia: prevalence, experience and cost*, expenditure on pharmaceuticals for incontinence was erroneously reported at $3.1 million.

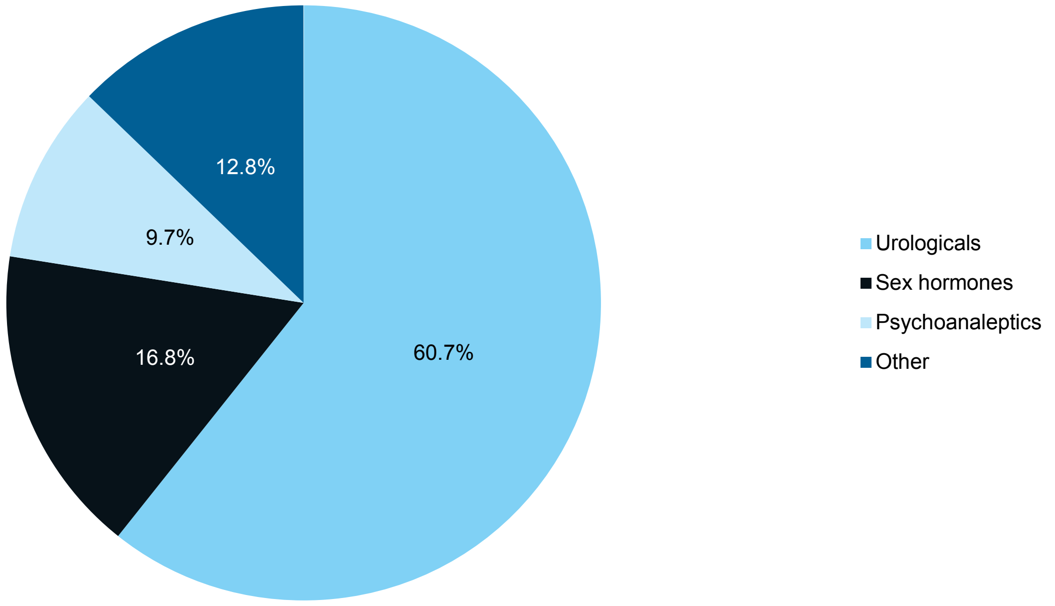
Source: AIHW Disease expenditure database.

Only 2% of prescribed drugs for incontinence were for fecal incontinence. However, there were 4.5 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 expenditure in Australia for incontinence for non-admitted patient services, other health professional services or over-the-counter medicines. 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 expenditure for non-admitted patient services is included in the specialist attendances and other MBS medical services 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 projects to improve the awareness, prevention and management of incontinence. In 2009–10, expenditure for the NCMS decreased to $2.8 million (DoHA unpublished data).



Source: AIHW Disease expenditure database.

Note: The 'Other' category includes anti-diarrheals, anti-bacterials, functional gastro-intestinal disorders, pituitary and hypothalamic hormones, mineral supplements, analgesics and other prescription pharmaceuticals.

Figure 6.1: Proportion of pharmaceutical expenditure on continence management for different pharmaceuticals (%)

Stoma appliances

A stoma is an artificial opening in the bowel or urinary system that has been deliberately made to divert the flow of faeces or urine. Stomas may be formed to manage urinary or fecal incontinence (Brown Hannah & Randle 2005). The Australian Government subsidises the Stoma Appliance Scheme (SAS), which provides stoma-related products free to people with stomas. To be eligible, a person must have a temporary or permanent artificial body opening (whether surgically created or otherwise) that facilitates the removal of urine or products of the gastrointestinal tract. The Australian Government provided $67.6 million for the SAS in 2008–09 and $72.0 million in 2009–10 (DoHA unpublished data).

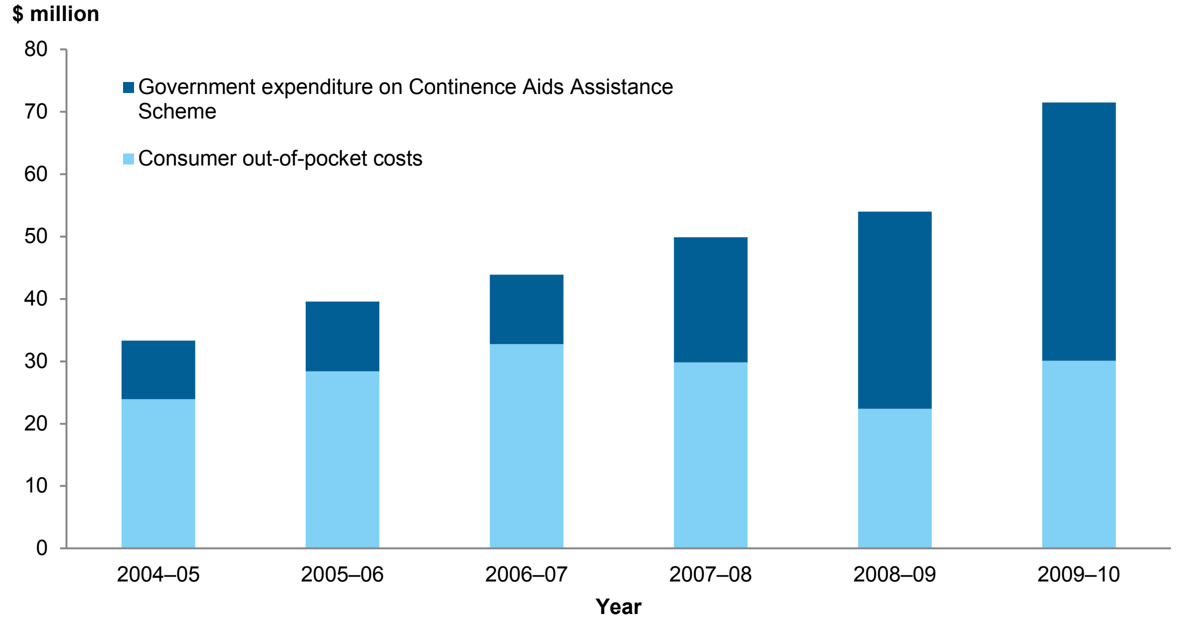
Continence aids

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 help members of the community with permanent and severe incontinence. It provides financial aid for continence products such as pads and catheters to help ease the burden on sufferers and enable them to maintain a level of participation in the community.

Industry sources indicate that the wholesale expenditure for continence aids bought 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. In 2009–10, supermarket expenditure on continence aids was $71.5 million (Gloria 2010) and CAAS expenditure was $41.1 million (DoHA unpublished data).

This suggests that community out-of-pocket costs were $30.1 million—for more information, see Figure 6.2 and Box 6.3: Consumer out-of-pocket costs for continence aids.

From 1 July 2010, the Continence Aids Payment Scheme (CAPS) replaced the CAAS. CAPS is an Australian Government payment that helps people who have permanent and severe incontinence meet some of the costs of their continence products.



Note

1. See Appendix Table A24 for data in this figure.

2. Costs expressed in current prices.

Source: AIHW analysis of DoHA unpublished data and Gloria 2004, 2005, 2006, 2007, 2008, 2009, 2010.

Figure 6.2: Expenditure on continence aids by source of expenditure, 2004–05 to 2008–09.

Box 6.3: Consumer out-of-pocket costs for continence aids

For people with incontinence and their carers, the impact on their potential for paid employment, and the additional expenses they face for continence aids, can increase the burden of the condition (see Chapter 4 for more detail).

From 2006–07 to 2009–10, the Australian Government increased CAAS funding by an average of 34.6% per year. This was accompanied by a steady decrease in consumer out-of-pocket costs on continence aids between 2006–07 and 2008–09 of 17.3% per year; however, from 2008–09 to 2009–10, consumer out-of-pocket costs increased by 34.3%—a similar rate to the CAAS funding increase of 31.1% (Figure 6.2).

With the ageing of the population, an increasing number of people are likely to experience incontinence, which is likely to increase demand for continence aids. Ongoing monitoring of CAAS funding and out-of-pocket costs is required to gauge the economic impact of the condition.

Burden of incontinence

Burden of disease is a term used to quantify the effect of a health issue. It uses measures such as financial cost, mortality, morbidity (the effect of ill health) and years affected by a condition. One common measure is the disability adjusted life year (DALY). The DALY describes the amount of time lost due to both fatal and non-fatal events—by combining the years of life lost and years of 'healthy' life lost due to disability.

Incontinence is not a fatal condition and therefore does not lead to burden due to premature death; however, it does decrease a person's quality of life. The DALY is a useful indicator of the burden of incontinence because it includes the effect on quality of life, or years of healthy life lost, due to incontinence.

The AIHW has released two reports with information on the burden of incontinence in Australia. Each used a different method of calculating burden and for this reason the estimates are complementary, but not comparable.

The *Australia incontinence data analysis and development* report (AIHW 2006) presented burden of disease analysis for incontinence using three primary data sources: the 2004 SAHOS, the RCS and the 2003 ABS SDAC CURF. Prevalence estimates were combined with severity data and disability weights to determine the years of healthy life lost due to incontinence for people in residential aged care and households.

Using the above method, it was estimated that 175,300 healthy life years were lost due to incontinence. Of this burden:

- 39,200 healthy life years were lost for people in residential aged care due to incontinence
- 122,000 healthy life years were lost for people in households due to urinary incontinence
- 14,100 healthy life years were lost for people in households due to fecal incontinence.

The SAHOS has not collected incontinence-related information since 2004. As a result, an update of this analysis has not been pursued because changes in patterns of incontinence suggest that assumptions based on the 2004 SAHOS data would not be well-founded.

In 2007, the AIHW released *The burden of disease and injury in Australia* (AIHW: Begg et al. 2007). This report presents information on the burden of urinary incontinence only, using a different methodology to that used in the 2006 report on incontinence.

In the 2007 report, incidence rates were derived from an epidemiological modelling software package known as DisMod, using prevalence data reported in a review of Australian and international literature and from Women's Health Australia. This method relied on a number of assumptions in calculating the number of healthy life years lost due to urinary incontinence: that a number of diseases and injuries are associated with the condition (most of which are more prominent at older ages); that the underlying causes are multi-factorial and interrelated; and that while all disability from incontinence among younger men and younger and middle-aged women is considered burden due to incontinence, half that experienced by middle-aged and older men and older women is already captured under other conditions.

Using this method, the 2007 burden of disease report found that 8,263 healthy life years were lost due to urinary incontinence. Of this, 6,440 years were attributed to females and the remaining 1,823 to males. These levels of burden are much lower than the figure of 175,300 health life years lost reported in the 2006 AIHW report on incontinence. This is in part because the 2007 report focused only on urinary incontinence, and because of the large differences that arise from using different assumptions and sources of data.

Section 2 Developing Australian continence data standards

7 Continence standards

Purpose

It is clear from Section 1 of this report that there are a range of definitions of incontinence as well as differences in the types of information collected. Further, where information is collected, it is not always comparable with other data, due to differences in questions asked, measurement tools used and analysis undertaken.

For example, in the 2009 SDAC, incontinence severity is determined by the difficulty a person has in controlling their bladder or bowel, whether they need assistance with this, and whether incontinence aids were used. Comparable studies, such as the 2004 SAHOS, use established measurement tools such as the ISI (Hawthorne 2006). This variation can result in differing estimates of the numbers of sufferers of severe incontinence.

One way to overcome these differences, and the confusion that can arise, is to develop and apply a set of data standards, such as classifications, standard questions and agreed scales. Adherence to data standards ensures there is mutual understanding of the meaning of underlying concepts and promotes data consistency and comparability.

Section 2 of this report suggests a set of standard questions for collecting information on incontinence in Australia, to improve accuracy and comparability of data.

Background

In 2001–02, the AIHW was commissioned to review existing health and community care data sets to identify items that could contribute to monitoring, treatment and management of incontinence (AIHW 2002). This review concluded that variation in the definition of incontinence, and in incontinence-relevant items in Australian collections, limited the useability of data for monitoring prevalence.

In 2004, the Department of Health and Ageing (DoHA) again commissioned the AIHW to review continence-relevant data collections, this time to inform and make recommendations for harmonising established and future continence program data. DoHA commissioned an update of this work for the current report.

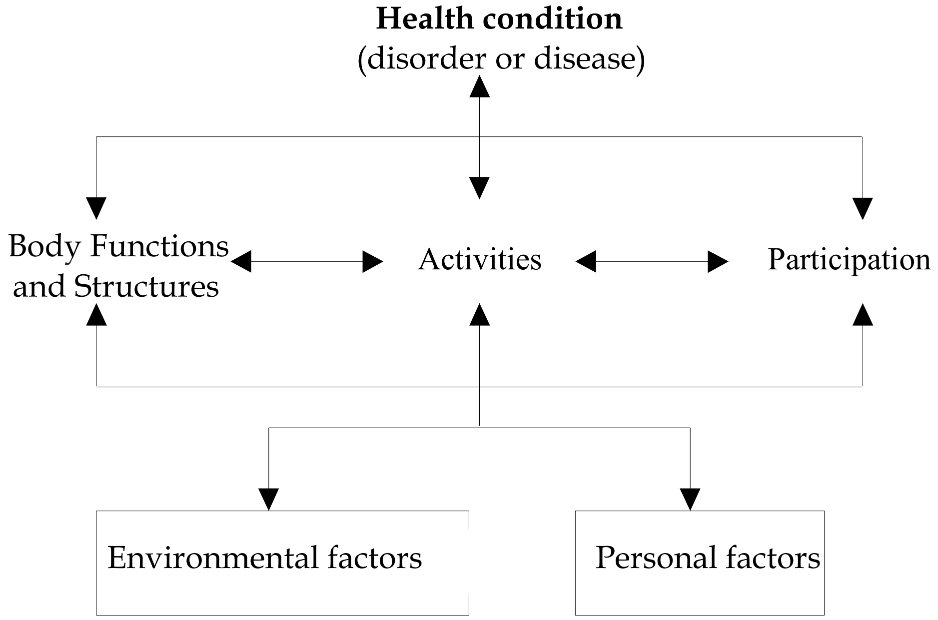
International Classification of Functioning, Disability and Health

The starting point for development of standard questions suggested in Chapter 10 is the ICF.

The ICF was endorsed by the World Health Assembly in 2001 (WHO 2001). It has been widely accepted as a framework for conceptualising disability and has been used in a range of applications (AIHW 2003), including by the ABS in Australian disability surveys (for example, ABS 2010).

Disability is a multidimensional concept, relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and the factors in their environment that affect these experiences (WHO 2001). The ICF framework has three components: Body Functions and Structures, Activities and Participation, and Environmental Factors (Figure 7.1).

Each component has a classification structure. For example, the Activities and Participation component comprises nine areas of life, including self-care, mobility and communication.



Source: WHO 2001.

Figure 7.1: Interactions between components of the International Classification of Functioning, Disability and Health

The first two components—Body Functions and Structures, and Activities and Participation—can be expressed in two ways. They can indicate neutral/positive aspects of health summarised under the term 'functioning', or they can be used to indicate problems (impairment, activity limitation or participation restriction). These problems are summarised under the umbrella term 'disability'.

Impairments are 'problems in body function or structure such as significant deviation or loss' in, for example, hearing or vision. Activity limitations are 'difficulties an individual may have in executing activities' such as eating or drinking. Participation restrictions are 'problems an individual may experience in involvement in life situations', such as participation in education and employment (WHO 2001:7–10).

Environmental factors and personal factors related to disability are also represented in the ICF. Environmental Factors 'make up the physical, social and attitudinal environment in which people live and conduct their lives'. Personal Factors are 'the particular background of an individual's life and living' (WHO 2001:16–17).

Method

For the 2006 AIHW report on incontinence, Australian data collections that gather information on incontinence were identified—this has been updated for the current report. The collections were investigated for all items relating to incontinence and toileting. Chapter 8 describes the collections; incontinence-relevant items in these collections are described in Chapter 9, along with a description of how they map to the ICF.

Data items were grouped and mapped with reference to the ICF. These items were compared, to determine the underlying themes in Australian incontinence data, and the sorts of items consistently included.

Incontinence assessment or outcome tools were also compared with information in Australian data collections. Again, these items were grouped and mapped with reference to the ICF, and assessed for data items for comparability and consistency.

The results of these mapping exercises, and reference to the content of incontinence assessment tools, were used to construct a list of data item options for use in future collections.

8 Australian continence data collections

Since 2006, there has been little change in data items used by Australian data collections that were presented in the AIHW report *Australian incontinence: data analysis and development* (AIHW 2006). The collections have either not released any new incontinence information, or new releases have not changed the data items included.

The new collections that are included in the results of the mapping exercise are:

- the ABS Australian Health Survey, which contains the same incontinence data as the National Health Survey, described in the 2006 report
- the Australasian Rehabilitation Outcomes Centre's Functional Independence Measure data
- the ACFI data—mapping of incontinence data on the ACFI replaces mapping on the RCS from the previous report
- the National Continence Program (NCP)/National Continence Helpline (NCH).

Apart from the NCH, data from Bladderbowel.gov.au and the National Public Toilet Map would be useful in specific analyses of the prevalence of particular needs, but are not directly relevant to developing a broader understanding of incontinence in Australia. Therefore they have not been included in the mapping exercise.

For more information on new collections and data items, see Chapter 9.

Population health and disability surveys

Survey of Disability, Ageing and Carers

The ABS SDAC is Australia's primary source of national population data on disability. Data are gathered from both households and cared accommodation and cover rural and urban areas in all states and territories. Information is collected on three population groups—people with a disability, older people (those aged 60 and over), and carers or persons who provide assistance to older people and those with disabilities. Six surveys have been conducted—in 1981, 1988, 1993, 1998, 2003 and 2009.

The definition of self-care in the SDAC follows the definition in the ICF (WHO 2001). It includes showering or bathing, dressing, eating, toileting, and bladder or bowel control (ABS 2010).

Incontinence-related data items collected in the SDAC include:

- self-care: level of assistance needed with bladder or bowel control (Table 9.2)
- uses aids for incontinence (Table 9.3)
- type of assistance primary carers usually provide: managing incontinence (Table 9.3) (ABS 2010).

National Health Survey and Australian Health Survey

The National Health Survey (NHS) is a population survey designed to obtain national benchmark information on a range of health-related issues, and to enable changes in health to be monitored over time (ABS 2009, 2012). Surveys were conducted in 1995, 2001, 2004–05 and 2007–08.

In 2011–12, the first Australian Health Survey (AHS) was conducted, incorporating the NHS. The AHS is the largest and most comprehensive health survey conducted in Australia. It combines the existing NHS and the National Aboriginal and Torres Strait Islander Health Survey with two new elements—a National Nutrition and Physical Activity Survey and a National Health Measures Survey.

The first results from the 2011–12 AHS survey covered four main areas:

- general health, including self-assessed health and psychological distress
- long-term health conditions, including arthritis, osteoporosis, asthma, cancer, diabetes mellitus, heart disease, mental and behavioural conditions and kidney disease
- health risk factors, including overweight and obesity, tobacco smoking, alcohol consumption, fruit and vegetable intake, exercise and children's risk factors
- physical measurements, including height and weight, waist circumference and blood pressure.

The NHS component of the AHS collects information on urinary incontinence as a long-term health condition; fecal incontinence is included in the category 'Diseases of the digestive system', and the subcategory 'Symptoms and signs involving the digestive system (ABS 2012).

Women's Health Australia

The Australian Longitudinal Study on Women's Health, or Women's Health Australia (WHA), is a large, longitudinal population-based survey that started in 1995 with an initial sample of 40,000 Australian women who have been followed to the present day. Researchers at the University of Newcastle and University of Queensland manage the survey and disseminate results. The study started in response to initiatives arising from the National Women's Health Policy. The purpose of the project is to provide scientifically valid information, based on current, accurate data that is relevant to the development of health policy and practice in women's health (see <http://www.alswh.org.au/>).

Three base-year survey cohorts representing young (aged 18–23), middle-aged (45–50) and older (70–75) women are surveyed every three years. Information is collected on six themes: physical and emotional health, use of health services, health behaviours and risk factors, time use, sociodemographic information, and life stages and key events. The study also links social, environmental and personal factors in women's lives to data on health-care, using the Medicare database.

Incontinence information is collected using the following question (Table 9.1):

> In the last 12 months have you had any of the following problems?
>
> Leaking urine: Never/Rarely/Sometimes/Often.

Data on the efficacy of health service intervention for treating incontinence are also collected, based on the respondent's self-rated satisfaction with services available (Table 9.3).

South Australian Health Omnibus Survey

The SAHOS was first conducted in 1991 and has run yearly since, primarily to assess health planning, delivery and evaluation (Taylor et al. 2006). The goal is to collect, analyse and interpret data, which can then be used to plan, implement and monitor health programs and other initiatives in South Australia.

The survey is a 'user-pays' service, where health organisations can buy questions for inclusion in respective surveys. The SAHOS is used by a number of government and non-government organisations. General results from each survey are provided to all clients, but responses to survey questions owned by different clients are not provided unless permission has been granted.

The population in scope are South Australians aged 15 and over living in private dwellings. Annually, 4,400 households are sampled and, with a response rate of around 70%, a minimum of 3,000 interviews are conducted. Information is collected on health conditions, risk factors and demographics. A series of questions derived from utility measures such as the EuroQOL, Assessment of Quality of Life instrument (AQoL) and HUI3 are also included, such as items on ease or limitation associated with executing activities (for example, mobility, communication) and feelings of community connectedness.

The SAHOS incontinence module comprises questions on experience of frequent urination and urine leakage, and leakage or loss of control of stools and gas (Table 9.1). Data on the need to wear continence pads for fecal incontinence are also collected (Table 9.3).

Australasian Rehabilitation Outcomes Centre

The Australasian Rehabilitation Outcomes Centre is a joint initiative of the Australian rehabilitation sector, and started operation on 1 July 2002. The AROC data set is owned by the Australasian Faculty of Rehabilitation Medicine and managed by the Centre for Health Services Development at the University of Wollongong. AROC's purpose and aims are to develop a national benchmarking system to improve rehabilitation outcomes, produce information on the efficacy of rehabilitation interventions, develop clinical and management information reports based on functional outcomes, promote education and certification in the use of the Functional Independence Measure (FIM™) instrument, provide annual reports summarising Australasian data and develop research proposals to refine outcome measures over time (see <http://ahsri.uow.edu.au/aroc/index.html>).

The AROC collects information on disability using the FIM™, which is a tool for measuring the severity of disability. It is comprised of 18 items, each of which is assessed against a 7–point ordinal scale where a higher score indicates a higher level of independent functioning for that particular item. FIM™ scores are taken on admission and discharge. There are three data items related to incontinence: Admission/Discharge FIM™ score for toileting, Admission/Discharge FIM™ score for bladder management, Admission/Discharge FIM™ score for bowel management.

Administrative data collections

Home and Community Care Minimum Data Set

Since 1 July 2012, the Australian Government assumed funding and operational responsibility of Health and Community Care (HACC) services for people aged 65 and over (50 and over for Aboriginal and Torres Strait Islander people). The state and territory governments fund and administer HACC-like services for people under the age of 65 (or under the age of 50 for Aboriginal and Torres Strait Islander people) (see <http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm>).

The Australian Government HACC program does not apply in Western Australia and Victoria, where services for all ages continue to be delivered by the state governments.

The HACC program funds services that support frail older people and their carers who live in the community and whose capacity for independent living is at risk of premature or inappropriate admission to long-term residential care. The program provides services such as domestic assistance, personal care as well as professional allied health care and nursing services, aids and equipment, transport, meals, home modifications and maintenance, and counselling, information and advocacy.

The HACC Minimum Data Set (MDS) is client-based and collected nationally by HACC agencies every 3 months. Data are forwarded to the HACC National Data Repository at DoHA. HACC agencies include those organisations or organisational sub-units responsible for the direct provision of HACC-funded assistance to clients. Data are only collected on clients who have received HACC-funded services from an agency within the 3-month reporting period. Therefore, not all clients or type(s) of assistance received will necessarily be included in each collection period (AIHW 2009).

Incontinence is not separately identifiable in the HACC MDS (V2.0) but it is subsumed within data items on assistance for personal care and self-care aids received. These items are:

- primary type of assistance received: personal care (includes toileting)
- assistance with goods and equipment received: self-care aids (includes aids that assist with urinary incontinence for example, bag, incontinence pad) and fecal incontinence (for example, colostomy bag, bowel pad) (Table 9.3).

A new data item 'Functional status—additional items' includes a code for toileting; that is, whether the person can manage the toilet, but no code for incontinence (Table 9.2).

Ongoing Needs Identification and Initial Needs Identification

The Ongoing Needs Identification (ONI) and Initial Needs Identification (INI) are two assessment tools developed by the Centre for Health Service Development at the University of Wollongong for use in various states and territories within HACC programs (see <http://ahsri.uow.edu.au/chsd/screening/index.html>).

The ONI, developed for use in New South Wales and Queensland, includes items on continence and incontinence in the Health Conditions Profile. It uses three incontinence items: experience of urine leakage, whether leakage events are related to coughing or sneezing, and experience of fecal soiling or change of bowel habit, which are documented in the Core ONI if identified as an issue for the client (Table 9.1). The Queensland version of the

ONI also uses a comment box to record any health conditions that may be associated with incontinence, and require further investigation.

The INI, developed for Victoria and South Australia, does not include specific questions on continence, although incontinence may be recorded within a section on (other) health conditions, where the client is asked to relate any relevant health problems experienced in the past that may relate to present problems or current conditions that are longstanding, persistent or recurrent. These issues may be recorded as requiring action.

Aged Care Assessment Program Minimum Data Set

The Aged Care Assessment Program (ACAP) is an Australian Government initiative where, under a cooperative working arrangement, the Australian Government engages state and territory governments to operate Aged Care Assessment Teams (ACATs) across Australia. ACAP's core objective is to comprehensively assess the care needs of frail older people and to help them gain access to the most appropriate types of care, including approval for Australian Government-subsidised aged care services (see <http://www.medicareaustralia.gov.au/provider/aged-care/assessment-program/index.jsp>).

The ACAP MDS is a client-centred data collection, designed to support program management and planning by supplying information about ACAT clients, their need for care and the outcome of their comprehensive assessment. The information collected by ACATs relates to client characteristics and circumstances, such as socio-demographic information, health status, functional abilities, current assistance from services, documentation of the assessment process, and components of the ACAT's care plan for the client, for example, recommended long-term care setting.

The data collection includes data on incontinence—defined as a health condition and body function impairment and detailed as:

- health condition, using ICD-10-AM codes: stress/urinary incontinence, bowel/fecal incontinence and unspecified urinary incontinence
- body function impairment (based on ICF): defecation functions, urination functions (Table 9.1); and as an activity limitation, although management of incontinence is not separately identifiable and categorised within self-care (Table 9.2).

Community Aged Care Packages

The Community Packaged Care Program comprises three levels of care: Community Aged Care Packages (CACPs), Extended Aged Care at Home (EACH) packages and Extended Aged Care at Home Dementia (EACHD) packages. The program was established in 1992 with the CACP, EACH and EACHD packages introduced in 1998 and 2004 respectively.

The Community Packaged Care Program provides coordinated care to assist frail older people to remain living at home. Packages are targeted at older people with needs that can only be met by a coordinated package of care services on an ongoing basis. Younger people with disabilities may also be assessed as eligible for a package where there are no other appropriate care options available.

From 1 July 2013, the Community Packaged Care Program will become the Home Care Packages Program. Subject to the passage of legislation, the CACP, EACH and EACHD packages will be replaced by four levels of Home Care Packages. A new dementia supplement will also be introduced to support people with dementia.

The Aged Care Funding Instrument

The ACFI was developed by DoHA and was introduced in March 2008 to allocate Australian Government subsidies to residential aged care providers (see <http://www.health.gov.au/acfi>).

The ACFI has 12 questions, of which question 4 relates to toileting needs and question 5 to continence. The response to question 5 is assessed by examining the continence records for the resident, which includes a 3-day urinary record and a 7-day bowel record. Diaries or logs completed in the 6 months before the ACFI appraisal may also be used if they accurately inform the continence record and reflect the resident's continence status at the time of the appraisal. Using these records, an 11-point check list is completed on urinary and fecal incontinence and a rating from A (continent) to D (always incontinent) is applied depending on how items were answered.

National Continence Program

The NCP was established in January 2011, replacing the National Continence Management Strategy (NCMS), which ran from 2008 to 2010. The program's overall aim is to improve awareness, prevention and management of incontinence so that more Australians and their carers can live and participate in the community with confidence and dignity.

The program is managed by DoHA and is the result of government policy direction, stakeholder input and an independent evaluation of the projects conducted under the NCMS (DoHA 2013a).

As well as producing and promoting a range of resources about bladder and bowel health, the NCP collects information on incontinence through the Continence Aids Payment Scheme and the National Continence Helpline.

Bladderbowel.gov.au

Bladderbowel.gov.au is a website managed by DoHA that provides information on bladder and bowel health, incontinence prevention and management for consumers, carers and health professionals. The website provides access to a range of continence resources and publications, and includes detailed information on previous projects under the NCMS.

Continence Aids Payment Scheme

The CAPS replaced the Continence Aids Assistance Scheme (CAAS) in July 2010. The CAPS is an Australian Government payment of up to $521 per year indexed annually that assists eligible people with permanent and severe continence to meet some of the costs of their incontinence products (DoHA 2013b).

To be eligible for a CAPS payment, individuals must have been assessed by a health practitioner as having permanent and severe loss of bladder and/or bowel function due directly to an eligible neurological condition or an eligible other condition if the client holds a Centrelink Pensioner Concession Card or DVA Pensioner Concession Card. For the purposes of CAPS, permanent and severe incontinence is defined as 'the frequent and uncontrollable; moderate to large loss of urine or faeces which impacts on a person's quality of life and is unlikely to improve with medical, surgical or clinical treatment regimes'.

The CAPS application form collects information on whether an individual has permanent and severe incontinence, permanent and severe loss of bladder function, permanent or severe loss of bowel function, and whether these conditions were caused by a neurological condition or an eligible other condition.

National Continence Helpline

The National Continence Helpline (NCHL) is a confidential and free national telephone service for consumers, carers and health professionals that provides practical information and advice, including access to a range of resources and details of the closest continence clinic. The helpline is staffed by continence nurse advisers and is managed by the Continence Foundation of Australia. Information collected during each call is entered into the helpline database. Depending on the nature of the call, data may be collected on the:

- nature of the call (for example, type of incontinence, aids and equipment)
- reason for call (for example, product and surgical procedure information, financial assistance, educational literature, preventative measures)
- caller type (professional, carer or client)
- response to call (for example, referral, literature sent)
- caller characteristics (for example, age, gender, ethnicity).

The Continence Foundation collates half-yearly results for analysis and reporting to DoHA.

The NCHL includes two relevant data items—continence issue, where the type of incontinence is recorded (Table 9.1), and reason for call, where clients may be ringing for information on aids and equipment (for example, their use, access) (Table 9.3).

The National Public Toilet Map

The National Public Toilet Map is a website funded as a part of the NCP and provides information on more than 16,000 public toilets throughout Australia. It can be searched for toilet locations by town, suburb, major parks and roads, and also features trip planning functions. Information provided about each toilet includes the location, opening hours, availability of baby changing rooms and accessibility for people with disability.

The NPTM is also available through any mobile device with an internet browser, and an iPhone application has also been developed. There is also a dedicated helpline that can provide assistance via email, fax or telephone. A range of data is collected about the use of the website, including the number of visitors (per day and time spent), favourite hot spots, and use via mobile and other electronic devices.

DoHA receives quarterly reports on usage and downloads from the NPTM.

Health service data collections

Bettering the Evaluation and Care of Health

The BEACH project is a continuous collection of morbidity and treatment data from a random sample of 1,000 GPs across Australia who each provide information on about 100 GP–patient encounters.

About 20 GPs participate each week, 50 weeks a year. As of July 2012, the BEACH database contained about 1,400,000 GP–patient encounter records (see <http://www.fmrc.org.au/beach.htm>).

BEACH aims to provide a quality database of GP-patient encounter information from which general practice data can be used by government bodies, GP organisations, consumers, researchers and the pharmaceutical industry, among others. BEACH uses three interrelated data collections: encounter data (for example, reasons for encounter, problems managed, medications prescribed, referrals, tests ordered and other treatments); GP characteristics (for example, age, sex, years in practice, practice size); and patient characteristics (for example, age, sex, Aboriginal and Torres Strait Islander status). It is a cross-sectional, paper-based data collection and has been developed and validated over 30 years at the University of Sydney.

Data items on incontinence from the BEACH collection include reasons for encounter and problems managed, coded using ICPC–2 PLUS (Table 9.1). Medical interventions prescribed to alleviate incontinence are recorded in the data items clinical treatment, imaging and pathology tests ordered, and medications/vaccinations prescribed for diagnosis/problem (Table 9.3).

Department of Veterans' Affairs Community Nursing Program

The DVA Community Nursing Program provides entitled veterans and war widow/widowers with a range of health-care and related services, including community nursing services.

DVA requires that all DVA-contracted community nursing providers submit data on all the community nursing services delivered to a veteran or war widow/widower in a 28-day claim period. The data is used by DVA to monitor the provision of services and inform research into policy development (DVA 2013)

Data submitted includes items about the person receiving service and the staffing resources required to provide service within 28 days, as well as assessment data, which includes an item on need for assistance while toileting. Need for assistance is calculated using one of four specified data collection instruments relating to the activities of daily living.

National Hospital Morbidity Database

The National Hospital Morbidity Database is a compilation of electronic summary records collected in admitted patient morbidity data collection systems in Australian hospitals. Data related to admitted patients in almost all hospitals are included: public acute hospitals, public psychiatric hospitals, private acute hospitals, private psychiatric hospitals and private free-standing day hospital facilities (AIHW 2012e).

The database records information on 'hospital separations' and not patients, where a separation refers to the episode of care, which can be a total hospital stay, from admission to discharge, transfer or death, or a portion of a hospital stay beginning or ending in a change in type of care (AIHW 2012d). Diagnoses, procedures and external causes are recorded.

Incontinence may be recorded, using ICD-10-AM codes, as a principal diagnosis responsible for a patient's episode of care in hospital, or an additional diagnosis. Data items on surgical and non-surgical procedures that are relevant to incontinence are also included, again based on ICD-10-AM codes. For a list of procedure codes, see AIHW 2009.

Medicare Benefits Schedule

The MBS is a listing of the Medicare services subsidised by the Australian Government. It is managed by DoHA and administered by the Department of Human Services (DHS). The MBS applies subsidies to cover out-of-hospital medical services and medical services delivered in hospitals to private patients (Medicare 2013).

MBS data collected by DoHA cover only those services eligible for Medicare benefits, as listed in the MBS. The MBS data include Medicare item number, Medicare benefit, date of service and processing, provider number, recipient of the service and an indication of whether or not the item was provided in a hospital. MBS reports can be accessed from the DoHA website (see <http://www.health.gov.au/internet/main/publishing.nsf/Content/Quarterly-Medicare-Statistics>. Eight Medicare item numbers refer to procedures and operations used specifically for urinary or fecal incontinence (Table 9.3).

Pharmaceutical Benefits Scheme

The Pharmaceutical Benefits Scheme (PBS) is administered by the DHS. The PBS aims to provide timely, reliable and affordable access to necessary medicines. Under the scheme, the costs of medicines are subsidised for most medical conditions (see <http://www.pbs.gov.au/info/about-the-pbs>). The PBS data collection includes information on Government subsidised prescriptions dispensed to general patients and concessional card holders.

The PBS statistics website (see <http://www.pbs.gov.au/info/browse/statistics>) contains a link to the DHS statistics website which provides aggregate statistics for each state and territory, based on PBS item codes and Anatomical Therapeutic Chemical classification categories, as detailed in the Schedule of Pharmaceutical Benefits.

9 Mapping and comparability of continence data items

This chapter updates the mapping and comparability exercise undertaken in the 2006 AIHW report for all available incontinence data items. The second part of this chapter looks at comparability of the ICF with continence assessment tools. Two assessment tools have been added to this analysis, as they became available after the 2006 report—the Revised Urinary Incontinence Scale (RUIS) and the Revised Fecal Incontinence Scale (RFIS). For more information, see 'Functional outcome assessment tool and utility index items' later in this chapter. Information on the recently revised World Health Organization Disability Assessment Tool 2.0 has also been included for context.

Main groupings in the International Classification of Functioning, Disability and Health

This chapter focuses on a range of data collections and instruments used for measuring incontinence and disability and how they are related to the ICF (WHO 2001).

Continence data collected in Australia covers four primary types of data items:

- incontinence as an impairment
- incontinence as an activity limitation
- assistance needed to manage incontinence
- medical interventions to relieve incontinence, such as medications and surgical procedures.

Tables 9.1, 9.2 and 9.3 map these data items to the ICF. The first type of data item, on impairment, maps broadly to the ICF Body Functions classification under Genitourinary and reproductive functions, and more specifically to Urinary continence (ICF code b6202) and Fecal continence (ICF code b5253). The second type of data item, of incontinence as an activity limitation, maps to the ICF classification of Activities and Participation under Toileting (ICF code d530), and Regulating urination and Defecation (ICF codes d5300 and d5301, respectively).

The last two types of data items, relating to assistance needed to manage incontinence and medical interventions, relate to the ICF chapter Environmental Factors. These are factors that make up the physical, social and attitudinal environment in which people live and conduct their lives. Within these two types of data items, personal assistance, and aids and equipment used map to the chapter headings Products and technology (ICF code e1151) and Support and relationships (ICF code e340), respectively.

Medical treatment and intervention map to Medication prescription and use—ICF code e1101 Drugs and health services (ICF code e5800 Health services).

Results from the mapping exercise are in Tables 9.1, 9.2 and 9.3.

Data item comparability

This section describes the use of incontinence data items in Australian data collections (Tables 9.1, 9.2, 9.3) and the comparability of items between collections.

Most of the collections reviewed still do not include data items corresponding to the ICF component of Body Structures or other subcomponents of Activities and Participation. This is surprising considering that many assessment tools have a focus on these two aspects of incontinence (see Section 9.3 for further discussion).

As discussed previously, there has been little change in data items since the 2006 report.

Body Functions and Structures

Incontinence (ICF codes b6202 Urinary continence and b5253 Fecal continence)

Continence data items included in most data collections characterise incontinence as an impairment of urinary or fecal continence (Table 9.1).

The SDAC includes data items that describe incontinence as an impairment associated with a health condition (and as a self-care activity limitation—see below). That impairment may be identified as the main impairment associated with a condition, the impairment causing the most problems, or a long-term impairment/restriction.

The WHA and the SAHOS use impairment-related data items derived from a series of questions on typical problems associated with incontinence, for example, urine and fecal leakage and, in SAHOS, the bothersomeness and severity of that leakage. In SAHOS, up to eight urinary and seven fecal continence questions were used to determine the experience and severity of incontinence.

Impairment data items from population health and disability surveys are often used to estimate the prevalence of incontinence in Australia. However, the different definitions used in these collections may produce varying estimates, and could make comparison between estimates difficult. This difficulty is increased by some data collections, such as the NHS and ACAP MDS, and the INI assessment tools, using data items that describe incontinence as a health condition.

The ICF defines a health condition as a 'disease or disorder', and the context in which an impairment of a body function (or an activity limitation or participation restriction) exists. Further discussion on definition and prevalence estimates is in Section 1.

The BEACH survey uses two data items to indicate impairment (or health condition)—reason for encounter and problem managed—coded using ICPC–2 PLUS (also known as the BEACH coding system, based on the International Classification of Primary Care) (see <http://sydney.edu.au/medicine/fmrc/icpc-2-plus/>).

All collections allow differentiation between urinary and fecal incontinence, except the SDAC, which groups them together.

Activities and Participation

Toileting (ICF codes d5300 Regulating urination and d5301 Regulating defecation)

Information on toileting is almost exclusively collected in administrative data collections that measure the need for support in activities of daily living. Toileting maps to the ICF codes d5300 'Regulating urination' and d5301 'Regulating defecation', where regulating is defined as 'coordinating and managing, such as by indicating need, getting into the proper position, choosing and getting to an appropriate place, manipulating clothing before and after, and cleaning oneself after'. An individual who experiences difficulty completing any aspect of this activity is considered to have an activity limitation, which may be alleviated by some form of assistance.

Data items in the ACAP MDS, CACP and ACFI collections effectively define incontinence as an activity limitation, where the help or supervision of another person is needed (Table 9.2). The SDAC also includes a data item on activity limitation related to incontinence.

The collection of information on toileting differs between collections, and data items do not map exclusively to the ICF Activities and participation. This is particularly apparent for the items used in the SDAC. While the SDAC records limitations or difficulties managing incontinence, the data domains enlist assistance, support or equipment, which is more closely defined as environmental factors, as a means to measure that limitation or difficulty. For example, the SDAC data item refers to 'always, sometimes or not needing help or supervision with managing bladder and bowel control' (see Table 9.2).

Environmental Factors items

Assistance (ICF codes e1151 Assistive products and technology for personal use in daily living and e340 Personal care providers and personal assistants)

The concepts of assistance and equipment relate to the ICF component Environmental Factors, and more specifically to the areas of Products and technology (for aid and equipment use) and Support and relationships (for personal assistance).

Information on use of aids and equipment is collected in the NCH, CAPS, SDAC, SAHOS and HACC MDS collections. The NCH and CAPS collections provide more detail on types of aids. Continence aid use and need are identified more simply in the SDAC and HACC MDS collections—whether an individual uses aids for incontinence and the primary type of assistance received—although continence aids in the HACC MDS are grouped with self-care aids and are not separately identifiable. The SAHOS included a data item on need to wear continence pads for fecal incontinence, and the frequency of the need to use pads. This item complements the suite of data items used in SAHOS to measure severity of incontinence experienced.

While data items on personal assistance provided are collected in the administrative data collections HACC MDS, ACAP MDS and CACP, data are collected about self-care in other collections, with no specific detail on continence-related activities. The SDAC, however, does include a data item on personal assistance provided for managing incontinence but, unlike the data item on aid use, this item is collected from the perspective of the caregiver, not the person experiencing incontinence.

Medical treatment and procedures (ICF codes e5800 Health services and e1101 Drugs)

Data items on medical intervention are almost the sole focus in the health service collections BEACH, NHMD, MBS and PBS. In the ICF, medical treatment and procedures for incontinence map (roughly) to the area of Health services, ICF code e5800 (WHO 2001). However, mapping of procedures can be better matched and more detailed using other classification systems, namely the Australian Classification of Health Interventions and ICPC–2. The range of procedures potentially used to alleviate incontinence are too numerous to repeat here.

BEACH includes data items on clinical treatment prescribed and any tests (for example, pathology) requested by a general practitioner, from which incontinence may be inferred. Information on surgical and non-surgical procedures relevant to incontinence is collected in the NHMD (using ICD-10-AM codes) and MBS collections.

Drugs are another environmental factor that can alleviate an impairment or activity limitation such as incontinence. Three collections include data items on drugs prescribed or used to treat incontinence or related symptoms—BEACH (drug labels prescribed), PBS (drug items prescribed under the PBS), and NHS (medications used for genitourinary conditions). However, identification of drugs used specifically to manage incontinence is complex.

Table 9.1: Mapping of data items from Australian incontinence-relevant data collections to the ICF (Body Functions)

Body Functions: Incontinence (ICF codes b6202 Urinary continence and b5253 Faecal continence)									
Collection	**SDAC**	**NHS**	**WHA**	**SAHOS**[(a)]		**HACC MDS**	**ACAP MDS**	**CACP**	**ACFI**
Data item	Restriction or impairment causing the most problems Condition producing main restricting impairment Long-term restriction as a result of head injury, stroke or other brain damage		Experienced 'leaking urine' in the last 12 months?	Experienced following problems and how much bothered by them: (a) frequent urination (b) urine leakage (c) small amount of urine leakage Small amount of leakage (drops)?	Experienced urgent need to have a bowel movement that makes you rush to the toilet Experienced leakage, accidents or loss of control with (a) solid stool (b) liquid stool or (c) gas or (d) if you don't get to a toilet in time	2005: (i) Frequency of urine leakage (ii) Amount of urine lost (ii) Frequency of faecal leakage	Body function impairment		Completion of an 11-point checklist after conducting a continence assessment using a 3-day urine continence record and 7-day bowel continence record.
Data domain or codes	17 Incontinence (bladder or bowel)		1 Never 2 Rarely 3 Sometimes 4 Often	1 Not at all 2 Slightly 3 Moderately 4 Greatly 5 Refused	1 Never 2 Rarely 3 Sometimes 4 Often or usually 5 Always 6 Refuse	See footnote[(b)]	Four-digit code based on ICF: 6003: Defecation functions 7002: Urination functions		A: Continent B: Occasionally incontinent C: Frequently incontinent D: Always incontinent

(continued)

Table 9.1 (continued): Mapping of data items from Australian incontinence-relevant data collections to the ICF (Body Functions)

Body Functions: Incontinence (ICF codes b6202 Urinary continence and b5253 Faecal continence)								
Collection	**NCH**	**CAPS**	**BEACH**	**CNP**	**NHMD**	**MBS**	**PBS**	**AROC FIM™**
Data item	Continence issue	Permanent and severe incontinence	Reasons for encounter Problems managed		Principal diagnosis Additional diagnosis			The patient's FIM™ score for bladder management; the patient's FIM™ score for bowel management
Data domain or codes	Faecal Urinary Faecal and urinary	Urinary Bowel Urinary and bowel Neurological cause Other cause	ICPC-2 PLUS codes		ICD-10-AM codes			Codes 1–7, 1 being total contact assistance and 7 being complete independence

(a) Questions from 2004 SAHOS.

(b) Frequency of urine leakage: 0 Never, 1 Less than once a month, 2 One to several times a month, 3 One to several times a week, 4 Every day and/or night.
Amount of urine lost each time: 1 A few drops, 2 A little, 3 More.
Frequency of faecal leakage or loss: 0 Never, 1 Rarely (less than once in past 4 weeks), 2 Sometimes (less than once a week, but more than once in past 4 weeks), 3 Often or usually (less than once a day but more than once a week), 4 Always (more than once a day).

Table 9.2: Mapping of data items from Australian incontinence-relevant data collections to the ICF (Activities and Participation)

Activities and Participation: Self-care (Toileting) (ICF codes d5300 Regulating urination and d5301 Regulating defecation)								
Collection	**SDAC**	**NHS**	**WHA**	**SAHOS**	**HACC MDS**	**ACAP MDS**	**CACP**	**ACFI**
Data item	Level of assistance needed with bladder/bowel control				Functional status: ability to manage the toilet with or without help	Activity limitation: activity in which help or supervision of another individual is needed	Core activity in which the help or supervision of another individual is needed	
Data domain or codes	1 Always needs help or supervision 2 Sometimes needs help or supervision 3 Does not need help or supervision but has some difficulty 4 Has no difficulty with bladder or bowel control				Only toileting	Self-care Managing incontinence is not separately identifiable	4: Toileting 5: Managing incontinence	
Collection	**NCH**	**CAAS**	**BEACH**	**CNP**	**NHMD**	**MBS**	**PBS**	**AROC FIM™**
Data item				Existence of toileting limitations as assessed by an ADL tool				The patient's FIM™ score for toileting
Data domain or codes				Y—High dependency for toileting N—Low or no dependency for toileting				Codes 1–7, 1 being total contact assistance and 7 being complete independence

Table 9.3: Mapping of data items from Australian incontinence-relevant data collections to the ICF (Environmental Factors)

Environmental Factors: Assistance (ICF codes e1151 Assistive products and technology for personal use in daily living and e340 Personal care providers and personal assistants)									
Collection	**SDAC**		**NHS**	**WHA**	**SAHOS**	**HACC MDS**	**ACAP MDS**	**CACP**	**ACFI**
Data item	Uses aids for incontinence	Type of assistance primary carer usually provides to main recipient of care			Need to wear continence pad (bowel incontinence)	(i) Primary type of assistance received (ii) Assistance with goods and equipment received	Recommended formal assistance with activities	Type of assistance received	
Data domain or codes	1 Uses incontinence aid(s) 2 Does not use incontinence aid(s) but uses other aids(s) 3 Does not use aid(s)	1 Usually assists with managing incontinence 2 Does not usually assist with managing incontinence			1 Never 2 Rarely 3 Sometimes 4 Often or usually 5 Always 6 Refused	(i) 5: Personal care Toileting, not incontinence (i) Self-care aids Continence aids identified by the code (04) and (05) but are recorded as self-care aids	Self-care Incontinence is not separately identifiable	1: Personal care Personal care includes assistance with daily self-care tasks such as toileting and managing incontinence. Incontinence is not separately identifiable	
Collection	**NCH**[(a)]		**CAAS**	**BEACH**	**CNP**	**NHMD**	**MBS**	**PBS**	**AROC FIM™**
Data item	Continence issue Reason for call	Product currently used[(a)]	Type of CAAS aids received						
Data domain or codes	Aids and appliances		List of Service Administrator's catalogue codes						

(continued)

Table 9.3 (continued): Mapping of data items from Australian incontinence-relevant data collections to the ICF (Environmental Factors)

Environmental Factors: Medical interventions (ICF codes e1101 Drugs and e5800 Health services)								
Collection	**SDAC**	**NHS**	**WHA**	**SAHOS**	**HACC MDS**	**ACAP MDS**	**CACP**	**RCS/ACFI**
Data item		Medications used	Satisfaction with health services available to help with problem					
Data domain or codes		0037: Other genitourinary	1 Yes 2 No 3 Not applicable					
Collection	**NCH**	**CAAS**	**BEACH**	**CNMDSA**	**NHMD**	**MBS**	**PBS**	**AROC FIM™**
Data item			Drugs prescribed Imaging and pathology tests Clinical treatment	Procedure (surgical)	Procedures (surgical and non-surgical)	Procedures qualifying for Medicare Benefits	PBS drug items	
Data domain or codes			ICPC-2 codes	ICD-10-AM codes	ICD-10-AM codes	MBS item codes	PBS drug item codes	

(a) NCH product codes include CISC, commode, pan or urinal, cones, deodorant, chair pad, feminine hygiene pad, IDC or SP catheter, incontinence garments, penile pad, personal alarm, plastic sheet, anal or urethra plug, anal/urethral or stoma pouches, reused bed sheets or chair pads, skin-care products, towels/handkerchief/tissues, urodome and nil.

Comparability with continence assessment tools

The impact incontinence has on a person's general wellbeing is influenced not only by the type and severity of incontinence, but also by the person's environment, perceptions and how the condition affects them personally and socially. Authors such as Abrams et al. (2002b) and Thomas et al. (2006) have recommended that any assessment of an individual with incontinence should include:

- a history and general assessment, including questions on nature and duration of symptoms, previous surgical procedures, environment, mobility, cognitive status and bowel function
- recorded clinical observations using standardised and reproducible measures
- assessment of symptoms, such as frequency of incontinence, perceived quantity of leakage, and perceived impact of leakage where pelvic muscle and voluntary sphincter control are measured on a quantifiable scale
- measurement of symptoms (for example, urodynamics), using bladder and bowel charts, and so forth
- when appropriate presence of symptom indications
- further symptom and quality of life assessment, using functional outcome validated questionnaires.

Standard clinical tests, such as urodynamics assessments, tend to correlate poorly with symptoms and functional outcomes, so a broad range of continence assessment tools have been developed to measure both symptoms and effects on wellbeing. These tools comprise two main types—the assessment of symptoms of incontinence and the assessment of functional outcomes; that is, the effects of incontinence on quality of life. The latter group of tools are generally classified as either incontinence-specific or more generic (Naughton et al. 2004).

Functional outcome assessment tool and utility index items

The number of functional outcome assessment tools (and utility indexes) is extensive. The Continence Outcomes Measurement Suite Project investigated the tools to recommend specific ones for use in Australia by primary care practitioners involved in the delivery of health services to people with incontinence, specialist incontinence practitioners and incontinence researchers (Thomas et al. 2006). The tools were recommended after a review of the research literature, consultations with practitioners and discussion with measurement experts.

Five health-related quality of life indexes were included in the 2004 SAHOS, to evaluate the effect of incontinence and intervention on quality of life. The results indicated that while four of the five instruments produced similar scores and score variation, there were differences in sensitivity, and two instruments—AQOL and HUI3—proved to be better measures in terms of validity and reliability (Hawthorne 2006; Thomas et al. 2006).

Given the wide range of tools, a select, but representative, group has been chosen for the present study, to assess comparability. The selection was based on recommendations made in the 2006 paper by Thomas et al. *Continence outcomes measurement suite together with review of patient satisfaction measures*. This paper has been chosen for the authors' thorough review of common incontinence assessment tools, and formal scoring system, which easily compares tools for their suitability across domains and settings. Two additional tools have also been included, the RUIS and the RFIS, which were created and validated by the University of Wollongong after the publication of the COMS paper, and have been demonstrated as being both valid and reliable for measuring the extent of urinary and fecal incontinence (Sansoni et al. 2006).

The tools considered are:

- Wexner Faecal Continence Grading Scale (Wexner FCGS)
- Incontinence Severity Index (ISI)
- International Consultation on Incontinence Questionnaire (ICIQ)
- King's Health Questionnaire (KHQ)
- Urogenital Distress Inventory (UDI)
- 24 or 48 Hour Pad Test
- European Quality of Life Measure—5D (EQ5D)
- Assessment of Quality of Life (AQoL)
- Health Utilities Index—Version 3 (HUI3)
- SF®-36 Health Survey—Version 1 and 2 (SF36V1, SF36V2)
- Barthel Activities of Daily Life Index (Barthel)
- Functional Independence Measure (FIM™)
- RUIS
- RFIS.

As well, the generic World Health Organization Disability Assessment Tool (WHODAS) has recently been substantially updated to WHODAS 2.0 (WHO 2010b). Information on this is in Box 9.1.

Outcome assessment tool and utility index items are mapped to the ICF in Table 9.4. Continence tools focus on symptoms and their effects. Items map mainly to the ICF components of Body Functions and Structures, and Activities and participation respectively, and to a lesser extent to Environmental Factors.

Tools to assess the symptoms of urinary incontinence listed in Table 9.4 are the UDI, including the UDI 6 short form, KHQ, ISI, ICIQ, RUIS, RFIS and the Wexner FCGS. The urinary incontinence symptom tools focus specifically on frequency (KHQ and ISI), amount of leakage (UDI and ISI), type of incontinence (all except ISI), voiding problems (UDI and KHQ) and pain (UDI and KHQ). The Wexner FCGS scores frequency of different forms of fecal incontinence (solid, liquid and gas), use of pads, and effect on lifestyle. The RUIS and RFIS provide a score from 0–16 for urinary incontinence and 0–20 for fecal incontinence, with four possible severity levels, ranging from 'no incontinence' to 'severe incontinence'. These tools examine aspects such as urgency, frequency and volume, and an additional item for fecal incontinence on the effect on the individual's lifestyle.

Box 9.1 The World Health Organisation Disability Assessment Schedule

In 2010, the World Health Organisation released a substantially revised assessment tool, the Disability Assessment Schedule (WHODAS 2.0), which is a measure for assessing the effect of a medical condition or illness on a person's life.

While at the time of this report the WHODAS 2.0 had not yet been used in studies on incontinence in Australia, it has great value in assessing the influence on incontinence and other areas of disability in Australia.

The WHODAS 2.0 is designed to map exactly to the items within the ICF and to measure the limitations on activity and restrictions on participation experienced, irrespective of the medical diagnosis. This means someone diagnosed with the same form of incontinence may score differently on the WHODAS 2.0, and be assessed as having differing levels of disability caused by their illness, depending on how they react, and are affected by that illness.

The WHODAS 2.0 has been empirically validated and has been tested across different population groups.

It captures level of functioning across six domains:

Domain 1: Cognition—understanding and communicating.

Domain 2: Mobility—moving and getting around.

Domain 3: Self-care—attending to one's hygiene, dressing, eating and staying alone.

Domain 4: Getting along—interacting with other people.

Domain 5: Life activities—domestic responsibilities, leisure, work and school.

Domain 6: Participation—joining in community activities, participating in society.

These domains are designed to tap levels of functioning and the parallel level of disability. For instance, the level of functioning of a person's body functions and structures measures the level of impairment, the level of functioning in the activities sphere measures activity limitations, and functioning in the participation sphere measures participation restrictions.

The WHODAS 2.0 comes in three forms:

- a 36-item version, which can be self-administered, interviewer-administered and proxy administered
- a 12-item version which can also be self-administered, interviewer-administered and proxy-administered
- a 12+24-item version which can only be administered by interviewer or computer-adaptive testing.

The WHODAS 2.0 does not have the ability to measure the symptom-specific aspects of illness, such as volume, frequency or type of incontinence; however, it can measure the effect of symptoms on impairment and disability.

Source: WHO 2010b

Incontinence-specific quality of life tools mostly focus on the effect incontinence has on a person's participation in various life areas. The most common life areas covered in the tools and mapped to the ICF are:

- domestic life, which is the ability to carry out domestic and everyday actions and tasks, such as acquiring a place to live, doing the shopping, household maintenance and cleaning, and assisting others

- interpersonal interactions and relationships, which comprise the tasks and actions required for basic and complex interactions with people in an appropriate manner
- major life areas, comprising education, work, community, social and civic life; that is, the actions and tasks required to participate in life outside the family, in the community and other areas of life (WHO 2001).

These life areas relate to the more broadly defined participation groupings used in generic quality of life measures, for example, 'social limitations' and 'role limitations'.

In addition to the tools recommended by Thomas et al. (2006), there are generic health-related quality of life (HRQoL) measures. Unlike most incontinence-specific tools, HRQoL tools measure the effect on activities, such as mobility and self-care (for example, hygiene, eating and drinking) and a range of body functions, such as cognition, vision, hearing and pain. In their review, Thomas et al. did not recommend any HRQoL tools as: there were no global quality of life measures for all pelvic floor conditions that incorporated incontinence, instruments were too generic, problems existed with standardising scoring and comparability between patients, and patients should have been believed when they said that life quality had improved or declined, despite what may they might score on a test.

Emotional response to incontinence is another important item included in incontinence-specific and generic quality of life measures, such as depression, anxiety, embarrassment and frustration. These responses are in part a result of the attitude of others towards incontinence (another environmental factor) but also the individual's feelings about the condition, especially for those with severe incontinence.

With the exception of the Wexner FCGS, which includes an item on protection use, there is little consideration of equipment and products used to manage incontinence or the sorts of environmental factors that could improve manageability of incontinence. AQoL scores the frequency of use of medical aids and visits to health professionals.

Table 9.4: Mapping of items from continence assessment tools to the ICF

Body Functions					
Chapter heading (ICF)	**ICF code(s)**	**Item**	**Assessment tool**		
			Symptom-specific	Incontinence-specific quality of life	Generic/utility index/quality of life
Mental functions	b130 Energy and drive functions	Energy		KHQ	SF-36
	b134 Sleep functions			KHQ	
	b152 Emotional functions			KHQ	AQoL, HUI3, EQ5D, SF-36
	b164 Higher-level cognitive functions	Cognition			HUI3
Sensory functions and pain	b210 Seeing functions				AQoL, HUI3
	b230 Hearing functions				AQoL, HUI3
	b280 Sensation of pain	Discomfort and pain	UDI, KHQ		AQoL, HUI3, EQ5D, SF-36
Functions of the digestive, metabolic and endocrine systems			Wexner FCGS		
Genitourinary and reproductive functions	b610 Urinary excretory functions b620 Urination functions b630 Sensations associated with urination functions	Incontinence symptoms	KHQ, UDI, ICIQ, ISI, RUIS, RFIS		
Activities and participation					
Chapter heading	**ICF code(s)**	**Item**	**Assessment tool**		
			Symptom-specific	Incontinence-specific quality of life	Generic/utility index/quality of life
Communication	d310 Communicating with—receiving—spoken messages and d330 Speaking				AQoL
Mobility	d440 Fine hand use	Dexterity			HUI3
	d450–d469 Walking and moving	Ambulation			HUI3, EQ5D
	d470–d489 Moving around using transportation	Travelling by car or bus			AQoL

(continued)

Table 9.4 (continued): Mapping of items from continence assessment tools to the ICF

Activities and participation (continued)					
Chapter heading	**ICF code(s)**	**Item**	**Assessment tool**		
			Symptom-specific	Incontinence-specific quality of life	Generic/utility index/quality of life
Self-care		Personal care and hygiene			EQ5D
Domestic life	d640 Doing housework	Housework			AQoL
	d650 Caring for household objects	Maintenance work			AQoL
Interpersonal interactions and relationships	d750 Informal social relationships	Relationships		KHQ	
	d7500 Informal relationships with friends	Visiting friends			AQoL
	d760 Family relationships	Family life			AQoL
Community, social and civic life	d920 Recreation and leisure	Recreational activities	RFIS, RUIS		AQoL
	d9205 Socialising	Social life		KHQ	
Environmental Factors					
Chapter heading	**ICF code(s)**	**Item**	**Assessment tool**		
			Symptom-specific	Incontinence-specific quality of life	Generic/utility index/quality of life
Products and technology	e1101 Drugs	Use of prescribed medicine			AQoL
	e1151 Assistive products and technology for personal use in daily living	Protection use and type	Wexner FCGS		AQoL
Support and relationships	e355 Health professionals	Medical treatment from doctor or health professional			AQoL

Notes

1. For explanation of acronyms of tools referred to in this table, see the section ‘Functional outcome assessment tool and utility index items’.
2. A small proportion of assessment tools assess effect on ‘everyday life’, ‘lifestyle’ or ‘usual activities’ etc. rather than defining specific activities, and these items therefore cannot be mapped to the ICF. These include the Wexner Feacal Grading Incontinence Score, ICIQ and EQ5D.

Sources: Bergner et al. 1981; Donovan et al. 1996; Handa & Massof 2004; Hawthorne 2006; Health Utilities Incorporated 2004; Kelleher et al. 1997; Lubeck et al. 1999; Naughton et al. 2004; Robinson & Shea 2002; Shaw et al. 2004; Thomas et al. 2006; Van der Vaart et al. 2003.

Comparability with Australian incontinence data items

Comparing Tables 9.1–3 and 9.4 shows some overlap between information collected in Australian data collections and incontinence assessment tools. This is largely in the Body Functions component, with only minimal overlap in other components. Body Functions items used in assessment tools tend to be more detailed than those collected in data collections.

The most consistent difference between assessment tools and incontinence data collections is the coverage of participation and, to some extent, activities and environmental factors. All the quality of life tools, and some symptom-based tools, include activity and participation items and, while the breadth of these items varies between tools, most have items where respondents rate how incontinence has affected their domestic life, relationships, employment and community and social life. None of the data collections include data items on participation as affected by incontinence specifically, although generic participation items in collections such as the SDAC do allow analytical investigation of participation restrictions associated with incontinence.

In contrast, continence assessment tools tend not to look at the sorts of environmental factors that may affect experience of incontinence, whereas many of the data collections do. For example, the omission of equipment and assistance in assessment tools—the Wexner FCGS is the only tool reviewed here that includes an assistance item, in this case protection use and type. Assistance is not consistently covered in Australian data collections but some sort of relevant 'assistance' data item(s) are included in the four administrative data collections and the SDAC.

10 Promoting consistency in data collections

As described in Chapter 9, the mapping of data items to the ICF in this report has only changed moderately since the 2006 report, *Australian incontinence: data analysis and development (*AIHW 2006).

The most significant additional data items since the 2006 report are those in the AROC FIM™ and the RFIS and RUIS. These items have contributed to the range of incontinence data available and tools that can be used to measure intervention outcomes, but they do not include elements missing from potential data items suggested in the 2006 report.

A menu of data items

The differences in purpose and context of the data collections reviewed have produced varying interpretations of incontinence (for example, incontinence as a body function impairment compared with incontinence as an activity limitation). Hence, the range of data items used to collect information on incontinence also varies. None of the collections reviewed used a definition of incontinence—some implied a definition but most described data items relevant to incontinence from which a user could create their own definition and estimate prevalence numbers.

The purpose of this chapter is not to define incontinence but to suggest potential data items that could be used in a range of collections and assessment tools. Use of these items could promote greater consistency and comparability of data.

The recommendations listed below were originally developed in 2006 with reference to both the general themes currently collected in Australian data collections and those in continence symptom and quality of life assessment tools. These have been updated slightly in the light of new collections and outcome tools described in the previous two chapters.

In the process of developing the recommendations, it was essential that proposed data items could be used independently, but also used together if needed. Items also needed to be applicable to different types of collections.

In summary, the following data items are proposed, and are described in detail, including the rationale for choosing them, and how they were derived:

- **Physical identification of incontinence:**
  - 1a: Incontinent of urine (control)
  - 1b: Incontinent of feces (control)
  - 1c: Strong urgency with urination or defecation
  - 1d: Type of urinary incontinence
- **Severity of incontinence—body function impairment:**
  - 2a: Frequency of urine leakage
  - 2b: Frequency of fecal leakage
  - 3: Amount of urine lost
  - 4a: Frequency of urination (day)

  - 4b: Frequency of urination (night)
  - 5: Frequency of bowel movements
- **6. Body function impairments associated with or coexistent with incontinence**
- **Incontinence as an activity limitation:**
  - 7: Difficulty and need for assistance with incontinence
  - 8: Frequency of need for assistance with incontinence
  - 9: Activity limitations/participation restrictions associated with incontinence
- **Aids and interventions:**
  - 10: Use of continence aids
  - 11: Type of incontinence aids used
  - 12: Other interventions for incontinence
  - 13: Type of additional intervention or support for incontinence
- **Carers**:
  - 14: Hours of caring due to incontinence
  - 15: Effects on carer physical and emotional wellbeing due to incontinence.

Proposed data items

The proposed data items are described with reference to the ICF components of Body Functions and Structures, Activities and Participation, and Environmental Factors, and the concept of severity. Including some or all of these items in collections could potentially allow for other kinds of information about incontinence sufferers, such as demographic details.

Identifying incontinence

Incontinence can be identified using the ICF body functions codes for:

- Functions of control—b6202 Urinary continence (functions of control over urination) and b5253 Fecal continence (functions involved in voluntary control over the elimination function)
- Functions of frequency—b6201 Frequency of urination (functions involved in the number of times urination occurs) and b5252 Frequency of defecation (functions involved in the frequency of defecation).

The ICF also codes for Fecal consistency (b5251—consistency of faeces such as hard, firm, soft or watery) and Flatulence (b5254—functions involved in the expulsion of excessive amounts of air or gases from the intestines), which are more commonly collected in epidemiological and clinical studies, although the SAHOS does include related questions.

Since items on functions of control and frequency are collected in only a few Australian data collections reviewed, symptom assessment tools are used to identify proposed items.

Many assessment tools record incontinence in terms of episodes of leakage, soiling, and so forth, over a given period. For example, in the Urogenital Distress Inventory for Urge Incontinence, respondents are asked whether they have experienced any episodes of urine leakage in the last 4 weeks. A comparable data item based on this approach is in Box 10.1 (data item 1a). An item based on experience of leakage may be a better identifier of incontinence in scenarios where information is collected solely or partly on a self-reporting basis—not all respondents who experience leakage may consider themselves incontinent, and may not identify as having incontinence if simply asked whether they experience incontinence.

The data collected from data item 1a would provide an estimate of the population who experience some degree of incontinence. There is no clear consensus on the appropriate time period, so none is prescribed here.

Data item 1b captures the population who experience 'urgency', defined by Abrams et al. (2002: 168) as '…a sudden compelling desire to pass urine, which is difficult to defer'. Urgency may or may not result in an incontinent event and does not necessarily occur periodically. However, it is related to control and can involve considerable management to prevent this happening. This data item complements other items in Box 10.1 by including experiences that are associated with, or may lead to, incontinence.

The type of urinary incontinence experienced is detailed in data item 1d. Stress, urge and mixed incontinence are the main types of urinary incontinence information collected in clinical and epidemiological surveys. Two additional categories are included—nocturnal enuresis, for urine leakage occurring during sleep, and 'other', which incorporates less common types of incontinence.

Box 10.1: Physical identification of incontinence

Data item 1a: Incontinent of urine (control)

Definition: Whether a person has experienced an episode or episodes of urine leakage over a defined time period.

Example value domain:

1 Yes
2 No

Data item 1b: Incontinent of feces (control)

Definition: Whether a person has experienced an episode or episodes of fecal soiling/loss over a defined time period.

Example value domain:

1 Yes
2 No

Data item 1c: Strong urgency with urination or defecation

Definition: Whether a person experiences a strong sense of urgency to urinate or defecate.

Example value domain:

1 Strong sense of urgency to urinate
2 Strong sense of urgency to defecate
3 Strong sense of urgency to urinate and defecate
4 Neither a sense of urgency to urinate nor defecate

Data item 1d: Type of urinary incontinence

Definition: The primary type of urinary incontinence a person experiences.

Example value domain:

(continued)

Box 10.1 (continued): Physical identification of incontinence

1 Stress urinary incontinence (urine leakage occurring on effort or exertion, or on sneezing or coughing)
2 Urge urinary incontinence (urine leakage accompanied by or immediately preceded by urgency)
3 Mixed urinary incontinence (urinary leakage associated with urgency and also with exertion, effort, sneezing or coughing)
4 Nocturnal enuresis (urinary leakage occurring during sleep)
5 Other (may include overflow incontinence, neurogenic or reflex incontinence and dribbling)

(See Abrams et al. 2002a for terminology of types of urinary incontinence.)

Severity and body function impairment: interweaving presence and severity

Assessment tools, and population health surveys such as the SAHOS, rarely use data items measuring presence of incontinence, but rely more on items that incorporate severity scales to identify presence of leakage. This inclusion of a measure of severity within identifier items enables estimation of the overall population with incontinence, and the population experiencing more severe incontinence. Frequency of urination and defecation are often collected alongside, or sometimes instead of, leakage information. Frequency information provides a context to understand how changes from the norm may indicate the onset of incontinence. Both severity measures and frequency measures are commonly measured on a point scale.

Severity of incontinence in clinical and epidemiological settings is usually measured by the frequency of leakage, and the volume lost at each episode. These are measures of severity related to body function impairments.

Frequency of urination items, which relate to the ICF code 'functions of frequency', records how often an individual needs to urinate or defecate over a set period—over 24 hours for urination, and usually a week for defecation.

Frequency of leakage is usually scored against a 4- or 5-point scale, where a respondent indicates how often they experience leakage over a given period.

While these items are not mutually exclusive, they do provide different measures of incontinence, and all indicate an impairment with control and/or frequency of need to urinate or defecate. An item on frequency of urination and defecation also allows an assessment of the regularity of leakage against actual frequency. Further, frequent urination is a possible sign of future incontinence for those not yet reporting incontinence. Box 10.2 describes items (data items 2a and 2b) to measure severity of incontinence in terms of frequency of leakage, Box 10.3 includes an item on amount of urine lost during an incontinence event, and Box 10.4 presents data items on frequency of urination during the day and during the night, and frequency of defecation over the week (data items 4a, 4b and 5, respectively).

Box 10.2: Severity of incontinence—body function impairment (i)

Data item 2a: Frequency of urine leakage

Definition: How often a person experiences urine leakage.

Example value domain:

0 Never
1 Less than once a month
2 Once or more times a month but less often than once a week
3 Once or more times a week but less often than once a day
4 More than once a day

Data item 2b: Frequency of fecal leakage

Definition: How often a person experiences fecal leakage.

Example value domain:

0 Never
1 Less than once a month
2 Once or more times a month but less often than once a week
3 Once or more times a week but less often than once a day
4 More than once a day

Box 10.3: Severity of incontinence—body function impairment (ii)

Data item 3: Amount of urine lost

Definition: The amount of urine lost when a person experiences urine leakage.

Example value domain:

0 Does not experience urine leakage
1 A few drops
2 More than a few drops

Box 10.4: Frequency of urination and defecation—body function impairment (iii)

Data item 4a: Frequency of urination (day)

Definition: The frequency with which a person urinates during the day, or while awake.

Example value domain:

1 1–3 times a day
2 4–6 times a day
3 7–10 times a day
4 10 or more times a day

Data item 4b: Frequency of urination (night)

Definition: The frequency with which a person urinates during the night; that is, getting up during sleeping hours to urinate.

Example value domain:

1 1–2 times a night
2 3–4 times a night
3 5 or more times a night

Data item 5: Frequency of bowel movements

Definition: The frequency with which a person defecates on average.

Example value domain:

1 Once a week or less
2 Twice per week
3 3–4 times per week
4 5–6 times per week
4 Once per day
5 Two or three times a day
6 Four times a day or more

Related body function impairments

Incontinence may occur with, or contribute to, other body function impairments. Examples of impairments that coexist with incontinence, as regularly collected in assessment tools, include impairments of mental functions, (for example, cognition, frustration, anxiety), mobility, and sensory functions, such as pain. Measuring other impairments associated with incontinence provides a broader understanding of a person's functional status, including the additional health or other forms of care a person may need, or the possible combined effect on participation.

The ICF provides an extensive list of body functions, which can be used at various levels. The chapter headings listed in Box 10.5 represent the highest level of body functions domains in data item 6; more specific body functions fall within these chapters. Depending on the purpose of the item, and the collection itself, value domains for a data item on body function impairment will differ depending on level of detail needed.

It should be noted that some body function impairments are more likely to coexist with incontinence than others; for instance, impairments of functions listed in Chapter 6: Genitourinary and reproductive functions are commonly associated with incontinence. However, for completeness, all chapters have been listed under data item 6 below.

Box 10.5: Body function impairments associated with or coexistent with incontinence

Data item 6: Body function impairments associated with or coexistent with incontinence

Definition: Other body function impairments reported by a person experiencing incontinence. Impairments of body functions are problems in body functions such as a loss or significant departure from population standards or averages.

Example value domain (based on ICF chapter headings):

1 Mental functions
2 Sensory functions and pain
3 Voice and speech functions
4 Functions of the cardiovascular, haematological, immunological and respiratory systems
5 Functions of the digestive, metabolic and endocrine systems
6 Genitourinary and reproductive functions
7 Neuromusculoskeletal and movement-related functions
8 Functions of the skin and related structures.

Activities, participation and environment

Incontinence as an activity limitation

Continence, or the control of urination and defecation, can also be understood as a self-care activity; incontinence would then be a limitation of that activity. An activity limitation is defined in the ICF as ‘difficulties an individual may have in executing activities’ (WHO 2001: 10). The ICF code most relevant to incontinence as an activity limitation is d530: Toileting, defined as ‘planning and carrying out the elimination of human waste…, and cleaning oneself afterwards’. The relevant subcodes are:

- d5300 Regulating urination
- d5301 Regulating defecation.

Need for assistance

Data on the difficulties associated with toileting are often collected in Australian population and administrative data collections with reference to the need for assistance. In this context, the presence of incontinence is not the activity limitation (difficulty) itself, it is the inability to manage incontinence without assistance that is limiting. A data item solely focused on need for assistance, however, does not capture the whole population experiencing difficulty managing their incontinence, and hence an item must distinguish between people who experience difficulty but can still manage on their own, and those who require assistance.

The SDAC includes such an item. Data item 7, in Box 10.6, is based on this SDAC item and incorporates the concepts of difficulty and need for assistance to differentiate between three population groups: people who experience difficulty and need assistance at least sometimes to manage their incontinence, people who do have some difficulty but do not currently need assistance, and those who do not experience problems with incontinence. The first group targets the population who use or need formal interventions to manage their incontinence; the second group comprises people who may require assistance in the future.

The level of assistance needed to manage incontinence complements this data item, and is the focus of the following section on severity and activity limitation.

As well, a person may indicate that they have no difficulty managing incontinence as they use continence aids. This category has been included in data item 7 to capture the entire population defined as suffering from incontinence in Section 1 of this report.

Only people who use continence aids but who do not have difficulty with incontinence (category 4) are identified in this data item. More comprehensive data items specifically on continence aids are included in Box 10.9.

Box 10.6: Severity of incontinence (ii)

Data item 7: Difficulty and need for assistance with incontinence

Definition: Whether an individual experiences difficulty and the level of assistance needed to manage their urinary or fecal incontinence (that is, bladder or bowel control).

Example value domain:

1 Always needs assistance to manage incontinence
2 Sometimes needs assistance to manage incontinence
3 Does not need assistance but has some difficulty managing incontinence
4 Has no difficulty managing incontinence but uses continence aids
5 Has no difficulty with managing incontinence and does not use continence aids.

Frequency of need for assistance

Severity can also be measured by assessing a person's need for assistance with incontinence. This severity data item considers incontinence as an activity limitation. Some of the data collections reviewed already use variations on this, ranging from whether any support is needed to the amount of support needed. The former method is partly captured in data item 7 if a person reports they experience difficulty managing incontinence and need assistance.

How often a person needs assistance is another measure of severity. The SDAC has an item in which the respondent reports the frequency of assistance needed over a defined period. This data item (data item 8, in Box 10.7) can be collected alongside data item 7 to paint a broader picture of the assistance a person needs to manage their incontinence.

Box 10.7: Severity of incontinence (iii)

Data item 8: Frequency of need for assistance with incontinence

Definition: The frequency of assistance needed to manage incontinence (bladder or bowel control).

Example value domain:

0 Does not need assistance
1 Less than once a month
2 1–3 times a month but not as often as once a week
3 1–6 times a week but not as often as once a day
4 1–2 times a day
5 3–5 times a day
6 6 or more times a day.

Incontinence and participation restrictions/other activity limitations

The ability to participate in various life areas, or undertake activities, is the most frequently used measure in condition-specific assessment tools, but the SAHOS and SDAC are the only population surveys that collect information on the impact of incontinence on a person's life. Depending on the level of detail required, participation may focus on the effect incontinence has on lifestyle generally (as asked in SAHOS: Does bowel or stool leakage cause you to alter your lifestyle?) or on a specified list of activities and life areas relevant to the population in scope.

The ICF provides an extensive list of activities and life areas that can be used to guide selection of relevant life areas. For impairments of body function, it is recommended that the user refer to the 'Activities and participation domains' data item in the *National community services data dictionary* (Version 3.0) (AIHW 2012f).

Box 10.8 presents data item 9, based on the main Activities and participation category in the ICF. This item may be used to identify the effect that incontinence has on a person's ability to participate in these areas. It should be possible to record more than one response to this item.

Box 10.8: Incontinence and activity limitations/participation restrictions

Data item 9: Activity limitations/participation restrictions associated with incontinence

Definition: The activities and life situations in which a person experiences limitations or restrictions associated with, or affected by, their incontinence.

The value domain for this data item is the International Classification of Functioning, Disability and Health: Activities and participation. Chapter headings and sub-chapter headings are listed below. ICF-coded categories within these chapters and sub-chapters are included as categories that are likely responses associated with incontinence; these should be coded to their chapters and sub-chapters.

Example value domain:

Chapter 1 Learning and applying knowledge

1.1 Purposeful sensory experiences
1.2 Basic learning
1.3 Applying knowledge

Chapter 2 General tasks and demands

Chapter 3 Communication

3.1 Communicating—receiving
3.2 Communicating—producing
3.3 Conversation and use of communication devices and techniques

Chapter 4 Mobility

4.1 Changing and maintaining body position
4.2 Carrying, moving and handling objects
4.3 Walking and moving
  d450 Walking
  d455 Moving around
4.4 Moving around using transportation

Chapter 5 Self-care

  d510 Washing oneself
  d520 Caring for body parts
  d530 Toileting
  d540 Dressing
  d550 Eating
  d560 Drinking
  d570 Looking after one’s health

Chapter 6 Domestic life

6.1 Acquisition of necessities
  d6200 Shopping
6.2 Household tasks
  d640 Doing housework

(continued)

Box 10.8 (continued): Incontinence and activity limitations/participation restrictions

- d6501–6504 Maintenance work

6.3 Caring for household objects and assisting others

Chapter 7 Interpersonal interactions and relationships

7.1 General interpersonal interactions

7.2 Particular interpersonal relationships

- d7500 Informal relationships with friends
- d760 Family relationships

Chapter 8 Major life areas

8.1 Education

8.2 Work and employment

8.3 Economic life

Chapter 9 Community, social and civic life

- d920 Recreation and leisure
- d9201 Sport
- d9204 Hobbies
- d9205 Socialising
- d930 Religion and spirituality.

Environmental factors

Environmental factors are often neglected in data collections, despite their effect on a person's experience or management of a health condition, disability or impairment, and hence their functioning. Managing incontinence often relies on personal assistance, or the use of aids. A number of Australian data collections have some information on environmental factors, often incorporated within questions on support or assistance needed. Personal assistance is the primary or only form of support normally included in these collections—information on aids would also help.

The purpose of many health and community service data collections is to determine what assistance is needed and available. A template for an item on aids to manage incontinence is in item 10 (Box 10.9), along with an item on the types of continence aids that might be used (data item 11). The aids listed reflect aids and equipment specific to incontinence and exclude more generic items. For data item 11, provision should be made for more than one response to be collected.

Box 10.9: Incontinence—use of aids

Data item 10: Use of continence aids

Definition: Use of aids and equipment to manage incontinence (bladder or bowel control).

Example value domain:

1 Uses aids or equipment to manage incontinence
2 Does not use aids to manage incontinence.

Data item 11: Type of incontinence aids used

Definition: Type of aids and equipment used to manage incontinence (bladder or bowel control).

Example value domain:

1 Continence pads
    1.1 Disposable
    1.2 Reusable
2 Continence pants
    2.1 Disposable
    2.2 Reusable
3 Drainage bags and accessories
4 Bottles and urinals
5 Catheters and catheter accessories
6 Condom drainage systems/protective sheaths/external catheters
7 Urethral plugs/vaginal bows/penis clamps
8 Anal plugs/anal tampons/anus bags
9 Stomal appliances
10 Fecal softeners and suppositories
11 Enemas and suppositories
12 Continence sheets and waterproof seat covers
13 Other.

Medical interventions and prevention

A record of medical interventions provides an indication of the extent of more severe incontinence, by virtue of the need for intervention. Some information on interventions is available from collections such as the Medicare Benefits Schedule and BEACH collections, but data are difficult to reconcile because of the differences between populations considered. Item 12 potentially enables the collection of information on these interventions (Box 10.10). It should be possible to collect more than one response for this item as well.

Box 10.10: Incontinence—interventions

Data item 12: Other interventions for incontinence

Definition: Other forms of support or intervention used or undertaken to manage incontinence.

Example value domain:

1 Preventive measures, such as pelvic floor exercises
2 Management strategies, such as time voiding, double voiding, bladder retraining
3 Medications
4 Surgical procedures
5 Diagnostic tests
6 Other interventions.

Additional support

As stated earlier, data items on support should be able to distinguish actual use from additional need for support. Data item 13 (Box 10.11) serves as a template for identifying need for support or interventions to manage incontinence, from which more detailed items may be developed, such as frequency of need for particular forms of assistance. This item should allow for more than one response.

Box 10.11: Incontinence—type of additional intervention or support

Data item 13: Type of additional intervention or support for incontinence

Definition: The type of additional intervention or support to manage incontinence (bladder or bowel control).

Example value domain:

1 Additional need for personal assistance
2 Additional need for aids and equipment
3 Additional need for other interventions
4 Does not need additional assistance or intervention methods.

Additional items

Effect on carer wellbeing

The physical and emotional effects of caring for a person with incontinence, particularly someone with severe incontinence, can be substantial. Analysis in Chapter 5 showed that some carers who assisted another person with incontinence had felt a negative effect on their physical and emotional wellbeing.

Two data items that may be used to indicate the effect on carer wellbeing are in Box 10.12. These are modelled on items used in the primary carer component of the SDAC. Data item 14 measures the time, in hours, a carer spends assisting a person with their incontinence over a week. Two value domains are suggested: one where the carer estimates the hours spent on a daily or a weekly basis, without reference to value domain prompts, the second is based on the value domain used in the SDAC to measure the hours a carer assists a person with self-care. The latter option is less preferable as it is based on the hours spent assisting with any combination of self-care activities. Further work would be required to estimate the hours a carer spends assisting a person with incontinence to develop an appropriate domain.

Data item 15 allows the carer to indicate the physical and emotional consequences, if any, of caring for someone with incontinence. Each of the values in the value domain are drawn from questions asked of primary carers in the SDAC, and refer to the carer's physical and emotional response to the caring role, and the effect of the caring role on their relationship with the person being cared for, other family members and friends.

Box 10.12: Incontinence—effect on carer wellbeing

Data item 14: Hours of caring due to incontinence

Definition: Number of hours a carer spends in a week assisting a person in managing their incontinence
or

Number of hours a carer spends on a daily basis assisting a person in managing their incontinence.

Carer to estimate number of hours.

Example value domain:

1 <20 hours per week
2 20–39 hours per week
3 40+ hours per week

Data item 15: Effects on carer physical and emotional wellbeing due to incontinence

Definition: The effects on a carer's physical and emotional wellbeing associated with assisting a person to manage their incontinence.

Example value domain:

1 Feels weary or lacks energy due to caring role
2 Sleep frequently interrupted due to caring role
3 Feels worried or depressed due to caring role
4 Feels angry or resentful due to caring role
5 Relationship with person being cared for negatively affected due to caring role
6 Relationships with other family members negatively affected due to caring role
7 Relationships with friends negatively affected due to caring role

Risk factors

A range of risk factors identified for incontinence are described in Chapter 3. Including a data item on risk factors provides some indication about the health conditions, life events or other factors associated with incontinence. However, any recommendation for a data item on risk factors is affected by the changing relationship of these factors to the development and experience of incontinence; that is, some of these factors may be precursors to incontinence, or influence incontinence or be associated with incontinence. Thus, an item is not proposed at this stage.

Toileting and incontinence

Toileting, in its broadest sense, may be considered as both the ability to perform tasks associated with using the toilet and the ability to manage bladder and bowel control. Australian population surveys and various administrative collections, however, tend to differentiate between the two by including data items on ability to manage toileting (that is, tasks associated with using the toilet) alongside, or in place of, items on ability to manage incontinence. For example, the SDAC collects information on the need for assistance with toileting, which refers to any difficulty associated with using a toilet, and the need for assistance with bladder and bowel management, or difficulty associated with bladder and bowel control.

While the ability to use or manage the toilet and the ability to manage incontinence are related, they are not the same; thus, the use of an item on toileting alone is not necessarily a good indicator of the population who experience incontinence, or who need assistance with their incontinence. Careful wording of any question clearly defining that toileting includes bladder and bowel control as well as the ability to get to and perform tasks associated with using the toilet may encourage better reporting.

However, this approach masks the two different aspects of toileting and, hence, the different needs of the individual and the sorts of assistance appropriate to their needs. One option would be to include two items that clearly separate tasks of toileting from the management of bladder and bowel control as activities of self-care.

Appendix tables

Table A1: People with disability living in households, incontinence status, by age and sex, 2009

	Severe incontinence			Does not have severe incontinence			Persons
Age (years)	Number	Per cent (row)	Per cent (column)	Number	Per cent (row)	Per cent (column)	Number
Male							
0–39	30,692	6.1	15.7	468,893	93.9	13.1	499,585
40–64	13,169	1.9	6.7	689,579	98.1	19.2	702,748
65–84	22,253	3.8	11.4	557,961	96.2	15.6	580,214
85+	*5,780	*7.2	*3.0	74,290	92.8	2.1	80,070
0–64	43,861	3.6	22.5	1,158,472	96.4	32.3	1,202,333
65+	28,033	4.2	14.4	632,251	95.8	17.6	660,283
Total Male	*71,893*	*3.9*	*36.8*	*1,790,723*	*96.1*	*50.0*	*1,862,617*
Female							
0–39	26,420	6.5	13.5	379,545	93.5	10.6	405,965
40–64	30,223	3.9	15.5	741,769	96.1	20.7	771,993
65–84	47,955	7.9	24.6	556,878	92.1	15.5	604,833
85+	18,825	14.0	9.6	115,673	86.0	3.2	134,498
0–64	56,643	4.8	29.0	1,121,314	95.2	31.3	1,177,957
65+	66,780	9.0	34.2	672,551	91.0	18.8	739,331
Total female	*123,423*	*6.4*	*63.2*	*1,793,866*	*93.6*	*50.0*	*1,917,288*
Persons							
0–39	57,112	6.3	29.2	848,438	93.7	23.7	905,550
40–64	43,392	2.9	22.2	1,431,348	97.1	39.9	1,474,741
65–84	70,208	5.9	35.9	1,114,839	94.1	31.1	1,185,047
85+	24,604	11.5	12.6	189,963	88.5	5.3	214,568
0–64	100,504	4.2	51.5	2,279,786	95.8	63.6	2,380,290
65+	94,812	6.8	48.5	1,304,802	93.2	36.4	1,399,614
Total persons	**195,316**	**5.2**	**100.0**	**3,584,589**	**94.8**	**100.0**	**3,779,905**

* Estimate has a relative standard error of 25–50% and should be used with caution.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A2: People with disability living in households, characteristics, by incontinence status, 2009

	Severe incontinence			Does not have severe incontinence			Persons
	Number	Per cent (row)	Per cent (column)	Number	Per cent (row)	Per cent (column)	Number
Remoteness							
Major cities	131,350	5.4	67.2	2,315,196	94.6	64.6	2,446,546
Inner regional	48,690	5.3	24.9	873,948	94.7	24.4	922,638
Other areas	15,276	3.7	7.8	395,445	96.3	11.0	410,721
Country of birth							
Australia	142,702	5.1	73.1	2,633,162	94.9	73.5	2,775,864
Main English-speaking countries	22,298	5.4	11.4	387,105	94.6	10.8	409,402
Other	30,316	5.1	15.5	564,323	94.9	15.7	594,639
Main language spoken at home							
English	176,695	5.1	90.5	3,269,636	94.9	91.2	3,446,330
Other language	18,621	5.6	9.5	314,953	94.4	8.8	333,574
Total weekly cash income							
Not applicable	29,207	10.9	15.0	237,747	89.1	6.6	266,954
$1–$450	104,808	5.7	53.7	1,735,104	94.3	48.4	1,839,912
$451–$958	37,731	4.5	19.3	806,122	95.5	22.5	843,852
$959 and above	*4,440	*1.0	*2.3	459,876	99.0	12.8	464,317
Not known	19,130	5.2	9.8	345,740	94.8	9.6	364,870
Main source of cash income							
Not applicable	35,661	8.5	18.3	382,909	91.5	10.7	418,570
Employee income	12,308	1.4	6.3	846,322	98.6	23.6	858,630
Unincorporated. business income	**678	**0.6	**0.3	117,450	99.4	3.3	118,127
Government pensions and allowances	125,443	6.4	64.2	1,836,493	93.6	51.2	1,961,936
Other income	19,999	5.0	10.2	376,748	95.0	10.5	396,747
Not known	**1,227	**4.7	**0.6	24,667	95.3	0.7	25,894

(continued)

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A2 (continued): People with disability living in households: characteristics, by incontinence status, 2009

	Severe incontinence			Does not have severe incontinence			Persons
	Number	Per cent (row)	Per cent (column)	Number	Per cent (row)	Per cent (column)	Number
Government pensions, allowances or benefits							
Not applicable	29,207	10.9	15.0	237,747	89.1	6.6	266,954
Age Pension	71,155	6.7	36.4	983,940	93.3	27.4	1,055,095
Newstart, Sickness or Youth Allowance	*2,083	*1.5	*1.1	136,344	98.5	3.8	138,427
Mature Age Allowance, Wife Pension, Carer Payment, Widow Allowance or Partner Allowance	*4,628	*5.7	*2.4	75,905	94.3	2.1	80,533
Service Pension (DVA)	8,692	6.8	4.5	118,955	93.2	3.3	127,647
Disability Support Pension	41,751	7.3	21.4	528,506	92.7	14.7	570,257
Special Benefit or Don't know	**1,378	**15.8	**0.7	7,361	84.2	0.2	8,740
None of these	36,421	2.4	18.6	1,495,832	97.6	41.7	1,532,253
Persons	**195,316**	**5.2**	**100.0**	**3,584,590**	**94.8**	**100.0**	**3,779,905**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A3: People age 15 and over living in households, other health issues or restrictions, by incontinence status, 2009

	Has severe incontinence		Does not have severe incontinence		Persons
	Number	Per cent	Number	Per cent	Number
Whether has limited use of arms and/or fingers					
Has limited use of arms or fingers	37,892	22.8	296,048	8.8	333,940
Has full use of arms and fingers	128,217	77.2	3,050,794	91.2	3,179,011
Whether restricted in everyday activities by shortness of breath or difficulty breathing					
No shortness of breath or breathing difficulties	104,024	62.6	2,635,060	78.7	2,739,085
Has shortness of breath or breathing difficulties and is restricted	35,213	21.2	371,136	11.1	406,349
Has shortness of breath or breathing difficulties but is not restricted	26,871	16.2	340,646	10.2	367,517
Whether has a disfigurement or deformity					
Has a disfigurement or deformity	12,952	7.8	140,896	4.2	153,847
Does not have a disfigurement or deformity	153,157	92.2	3,205,947	95.8	3,359,104
Whether has blackouts, fits or loss of consciousness					
Has blackouts, fits or loss of consciousness	13,097	7.9	163,590	4.9	176,687
Does not have blackouts, fits or loss of consciousness	153,012	92.1	3,183,252	95.1	3,336,264
Whether has difficulty in gripping or holding things					
Has difficulty gripping or holding things	69,177	41.6	716,481	21.4	785,658
Has no difficulty gripping or holding things	96,932	58.4	2,630,361	78.6	2,727,293
Whether has limited use of legs or feet					
Has limited use of feet or legs	57,504	34.6	415,840	12.4	473,344
Has full use of feet and legs	108,604	65.4	2,931,002	87.6	3,039,607
Whether has chronic or recurrent pain or discomfort					
Has no chronic or recurrent pain or discomfort	66,703	40.2	1,765,188	52.7	1,831,891
Has chronic or recurrent pain or discomfort and is limited in activities	86,395	52.0	1,217,069	36.4	1,303,464
Has chronic or recurrent pain or discomfort but is not limited in activities	13,011	7.8	364,585	10.9	377,596
Whether is limited or restricted in doing everyday physical activities or physical work					
Limited or restricted in physical activities or in doing physical work	127,278	76.6	1,499,652	44.8	1,626,930
Not limited or restricted in physical activities or in doing physical work	38,831	23.4	1,847,190	55.2	1,886,021

(continued)

Table A3 (continued): People age 15 and over living in households, other health issues or restrictions, by incontinence status, 2009

	Has severe incontinence		Does not have severe incontinence		Persons
	Number	Per cent	Number	Per cent	Number
Whether has loss of sight					
No loss of sight	94,559	56.9	2,206,879	65.9	2,301,438
Loss of sight corrected by wearing glasses or contact lenses	50,453	30.4	942,187	28.2	992,640
Partial loss of sight not corrected by wearing glasses or contact lenses	18,772	11.3	189,004	5.6	207,776
Total loss of sight	**2,325	**1.4	8,773	0.3	11,097
Whether has loss of speech					
No loss of speech	146,113	88.0	3,262,514	97.5	3,408,627
Partial loss of speech	16,250	9.8	81,436	2.4	97,686
Total loss of speech	*3,746	*2.3	*2,892	*0.1	6,638
Persons	**166,109**	**100.0**	**3,346,842**	**100.0**	**3,512,951**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A4: People aged 15 to 64 with disability, living in households: labour force participation, by incontinence status, 2009

	Has severe incontinence		Does not have severe incontinence		Persons
	Number	Per cent	Number	Per cent	Number
Employed working full time	7,047	9.9	654,637	32.1	661,684
Employed working part time	10,633	14.9	396,635	19.4	407,267
Unemployed	**942	**1.3	87,956	4.3	88,898
Not in the labour force	52,675	73.9	902,812	44.2	955,488
Labour force participation rate (%)	–	*26.1*	–	*55.8*	–
Persons	**71,297**	**100.0**	**2,042,040**	**100.0**	**2,113,337**

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A5: People aged 15 to 64 with disability, living in households, labour force participation, by whether uses continence aids, 2009

	Uses continence aid(s)		Does not use continence aids but uses other aids		Does not use aids		Persons
	Number	Per cent	Number	Per cent	Number	Per cent	Number
Employed working full time	*3,320	*10.0	190,002	24.2	468,362	36.2	661,684
Employed working part time	7,047	21.2	142,206	18.1	258,015	19.9	407,267
Unemployed	**560	**1.7	28,233	3.6	60,104	4.6	88,898
Not in the labour force	22,296	67.1	424,091	54.1	509,100	39.3	955,488
Labour force participation rate (%)	–	*32.9*	–	*45.9*	–	*60.7*	–
Persons	**33,223**	**100.0**	**784,532**	**100.0**	**1,295,582**	**100.0**	**2,113,337**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A6: People aged 15 and over with disability, living in households, social participation, by incontinence status, 2009[(a)]

	Has severe incontinence		Does not have severe incontinence		Persons
	Number	Per cent	Number	Per cent	Number
Whether can leave home as often as would like					
Can go out as often as would like	74,375	44.8	2,420,809	72.3	2,495,184
Cannot go out as often as would like	87,073	52.4	895,773	26.8	982,845
Does not leave home at all	*4,661	*2.8	30,261	0.9	34,921
Persons	**166,109**	**100.0**	**3,346,843**	**100.0**	**3,512,951**

* Estimate has a relative standard error of 25–50% and should be used with caution.

(a) Excludes people who did not have personal interviews.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A7: People aged 15 and over with disability living in households who do not go out as often as they would like, main reason does not go out as often as would like, by incontinence status, 2009

	Has severe incontinence		Does not have severe incontinence		Persons
	Number	**Per cent**	**Number**	**Per cent**	**Number**
Could not be bothered or nowhere to go	*2,353	*2.7	95,313	10.6	97,667
Cost or can't afford to	*5,856	*6.7	100,886	11.3	106,742
Own disability or condition	59,384	68.2	390,491	43.6	449,875
Another person's disability or condition	*2,281	*2.6	61,564	6.9	63,845
Difficulty using transport	*1,320	*1.5	11,266	1.3	12,586
Difficulty obtaining transport	**773	**0.9	23,558	2.6	24,331
Children too young	**743	**0.9	15,955	1.8	16,698
Old age or too old	*1,718	*2.0	14,389	1.6	16,108
Not enough time	**582	**0.7	34,823	3.9	35,405
No carer to go with	*2,263	*2.6	9,315	1.0	11,578
No one to go with as a companion	*3,202	*3.7	24,562	2.7	27,764
Fear or anxiety	*4,742	*5.4	53,745	6.0	58,488
Other reason	*1,853	*2.1	59,907	6.7	61,760
Persons	**87,073**	**100.0**	**895,773**	**100.0**	**982,845**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A8: People aged 15 and over with disability, living in households: emotional wellbeing (self-rated), by incontinence status, 2009[(a)]

	Has severe incontinence		Does not have severe incontinence		Persons
	Number	**Per cent**	**Number**	**Per cent**	**Number**
How often felt calm and peaceful during last 4 weeks					
All of the time	10,828	8.8	368,136	12.2	378,964
Most of the time	33,724	27.3	1,054,716	35.1	1,088,440
A good bit of the time	18,458	15.0	437,761	14.6	456,219
Some of the time	28,506	23.1	640,637	21.3	669,143
A little of the time	24,448	19.8	355,649	11.8	380,098
None of the time	7,421	6.0	149,263	5.0	156,684
How often felt down during last 4 weeks					
All of the time	*6,782	*5.5	82,259	2.7	89,041
Most of the time	16,225	13.2	251,838	8.4	268,064
A good bit of the time	13,033	10.6	252,610	8.4	265,642
Some of the time	31,168	25.3	664,540	22.1	695,708
A little of the time	33,756	27.4	820,024	27.3	853,780
None of the time	22,422	18.2	934,891	31.1	957,314
How often had a lot of energy during last 4 weeks					
All of the time	*2,505	*2.0	178,649	5.9	181,154
Most of the time	10,975	8.9	644,301	21.4	655,276
A good bit of the time	12,426	10.1	420,046	14.0	432,472
Some of the time	26,799	21.7	758,464	25.2	785,263
A little of the time	36,812	29.8	608,659	20.2	645,470
None of the time	33,869	27.4	396,044	13.2	429,913
General health assessment					
Excellent	*3,241	*2.6	193,745	6.4	196,986
Very good	15,143	12.3	645,993	21.5	661,136
Good	35,685	28.9	1,108,321	36.9	1,144,007
Fair	41,919	34.0	746,149	24.8	788,068
Poor	27,397	22.2	311,954	10.4	339,352
Persons	**123,386**	**100.0**	**3,006,162**	**100.0**	**3,129,548**

* Estimate has a relative standard error of 25–50% and should be used with caution.

(a) Excludes 383,403 people (weighted) who were not personally interviewed.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A9: People with disability living in households, need for assistance with managing bladder or bowel control, by age and sex, 2009

	Always/sometimes needs help or supervision			Does not need help but has difficulty			Has no difficulty			Persons
Age (years)	**Number**	**Per cent (row)**	**Per cent (column)**	**Number**	**Per cent (row)**	**Per cent (column)**	**Number**	**Per cent (row)**	**Per cent (column)**	**Number**
Male										
0–39	27,832	5.6	20.0	11,466	2.3	3.6	460,288	92.1	13.9	499,585
40–64	11,867	1.7	8.5	44,206	6.3	13.7	646,675	92.0	19.5	702,748
65–84	15,858	2.7	11.4	46,298	8.0	14.4	518,058	89.3	15.6	580,214
85+	*4,676	*5.8	*3.4	10,292	12.9	3.2	65,102	81.3	2.0	80,070
0–64	39,699	3.3	28.6	55,672	4.6	17.3	1,106,963	92.1	33.4	1,202,333
65+	20,533	3.1	14.8	56,590	8.6	17.6	583,160	88.3	17.6	660,283
Total male	**60,232**	**3.2**	**43.3**	***112,261***	***6.0***	***34.8***	***1,690,123***	***90.7***	***50.9***	***1,862,617***
Female										
0–39	23,449	5.8	16.9	16,236	4.0	5.0	366,279	90.2	11.0	405,965
40–64	16,221	2.1	11.7	88,083	11.4	27.3	667,689	86.5	20.1	771,993
65–84	25,982	4.3	18.7	87,294	14.4	27.1	491,557	81.3	14.8	604,833
85+	13,129	9.8	9.4	18,352	13.6	5.7	103,017	76.6	3.1	134,498
0–64	39,670	3.4	28.5	104,319	8.9	32.4	1,033,968	87.8	31.2	1,177,957
65+	39,111	5.3	28.1	105,646	14.3	32.8	594,574	80.4	17.9	739,331
Total female	**78,782**	**4.1**	**56.7**	***209,965***	***11.0***	***65.2***	***1,628,542***	***84.9***	***49.1***	***1,917,288***

(continued)

Table A9 (continued): People with disability living in households, need for assistance with managing bladder or bowel control, by age and sex, 2009

	Always/sometimes needs help or supervision			Does not need help but has difficulty			Has no difficulty			Persons
Age (years)	**Number**	**Per cent (row)**	**Per cent (column)**	**Number**	**Per cent (row)**	**Per cent (column)**	**Number**	**Per cent (row)**	**Per cent (column)**	**Number**
Persons										
0–39	51,281	5.7	36.9	27,702	3.1	8.6	826,567	91.3	24.9	905,550
40–64	28,088	1.9	20.2	132,289	9.0	41.1	1,314,363	89.1	39.6	1,474,740
65–84	41,840	3.5	30.1	133,592	11.3	41.5	1,009,615	85.2	30.4	1,185,047
85+	17,805	8.3	12.8	28,644	13.3	8.9	168,119	78.4	5.1	214,568
0–64	79,369	3.3	57.1	159,991	6.7	49.7	2,140,931	89.9	64.5	2,380,291
65+	59,645	4.3	42.9	162,236	11.6	50.3	1,177,734	84.1	35.5	1,399,614
Total person	**139,014**	**3.7**	**100.0**	**322,226**	**8.5**	**100.0**	**3,318,665**	**87.8**	**100.0**	**3,779,905**

* Estimate has a relative standard error of 25–50% and should be used with caution.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A10: People with disability living in cared accommodation, level of need for assistance with managing bladder or bowel control, by age and sex, 2009

	Always/sometimes needs help or supervision			Does not need help but has difficulty			Has no difficulty			Persons
Age (years)	**Number**	**Per cent (row)**	**Per cent (column)**	**Number**	**Per cent (row)**	**Per cent (column)**	**Number**	**Per cent (row)**	**Per cent (column)**	**Number**
Male										
0–39	*608	*39.7	*0.5	**17	**1.1	**0.3	*905	*59.2	*2.6	*1,531
40–64	3,889	53.8	3.3	*339	*4.7	*5.7	2,999	41.5	8.5	7,227
65–84	16,482	72.2	14.1	732	3.2	12.3	5,613	24.6	16.0	22,827
85+	13,576	70.1	11.6	892	4.6	15.0	4,888	25.3	13.9	19,356
0–64	4,497	51.3	3.9	*357	*4.1	*6.0	3,904	44.6	11.1	8,758
65+	30,058	71.3	25.7	1,624	3.9	27.3	10,501	24.9	29.9	42,183
Total male	*34,555*	*67.8*	*29.6*	*1,981*	*3.9*	*33.3*	*14,405*	*28.3*	*41.0*	*50,940*
Female										
0–39	*312	*54.8	*0.3	**8	**1.3	**0.1	*250	*43.9	*0.7	*569
40–64	3,507	67.6	3.0	*164	*3.2	*2.8	1,519	29.3	4.3	5,189
65–84	28,790	76.3	24.7	1,262	3.3	21.2	7,669	20.3	21.8	37,721
85+	49,600	78.2	42.5	2,528	4.0	42.5	11,301	17.8	32.2	63,429
0–64	3,818	66.3	3.3	*172	*3.0	*2.9	1,768	30.7	5.0	5,758
65+	78,390	77.5	67.1	3,790	3.7	63.8	18,970	18.8	54.0	101,150
Total female	*82,208*	*76.9*	*70.4*	*3,962*	*3.7*	*66.7*	*20,738*	*19.4*	*59.0*	*106,908*

(continued)

Table A10 (continued): People with disability living in cared accommodation, level of need for assistance with managing bladder or bowel control, by age and sex, 2009

	Always/sometimes needs help or supervision			Does not need help but has difficulty			Has no difficulty			Persons
Age (years)	Number	Per cent (row)	Per cent (column)	Number	Per cent (row)	Per cent (column)	Number	Per cent (row)	Per cent (column)	Number
Persons										
0–39	919	43.8	0.8	**25	**1.2	**0.4	*1,155	*55.0	*3.3	2,099
40–64	7,395	59.6	6.3	*503	*4.1	*8.5	4,518	36.4	12.9	12,416
65–84	45,272	74.8	38.8	1,995	3.3	33.6	13,281	21.9	37.8	60,548
85+	63,176	76.3	54.1	3,420	4.1	57.5	16,189	19.6	46.1	82,785
0–64	8,315	57.3	7.1	*528	*3.6	*8.9	5,673	39.1	16.1	14,516
65+	108,448	75.7	92.9	5,414	3.8	91.1	29,470	20.6	83.9	143,333
Total person	**116,763**	**74.0**	**100.0**	**5,943**	**3.8**	**100.0**	**35,143**	**22.3**	**100.0**	**157,849**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A11: People with disability living in households, level of need for assistance with toileting, by age and sex, 2009

	Always/sometimes needs help or supervision		Does not need help but has difficulty		Has no difficulty		Does not use toilet		Persons
Age (years)	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**	**Number**
Male									
0–39	34,219	6.8	8,740	1.7	453,035	90.7	*3,592	*0.7	499,585
40–64	13,215	1.9	22,230	3.2	667,303	95.0	–	–	702,748
65–84	16,811	2.9	15,780	2.7	546,113	94.1	**1,510	**0.3	580,214
85+	*2,643	*3.3	*5,614	*7.0	71,812	89.7	–	–	80,070
0–64	47,434	3.9	30,970	2.6	1,120,338	93.2	*3,592	*0.3	1,202,333
65+	19,454	2.9	21,395	3.2	617,925	93.6	**1,510	**0.2	660,283
Total male	*66,888*	*3.6*	*52,365*	*2.8*	*1,738,263*	*93.3*	**5,102*	**0.3*	*1,862,617*
Female									
0–39	19,471	4.8	9,908	2.4	375,259	92.4	**1,328	**0.3	405,965
40–64	11,998	1.6	29,691	3.8	730,304	94.6	–	–	771,993
65–84	15,177	2.5	22,864	3.8	566,792	93.7	–	–	604,833
85+	9,733	7.2	7,963	5.9	116,552	86.7	**250	**0.2	134,498
0–64	31,469	2.7	39,598	3.4	1,105,562	93.9	**1,328	**0.1	1,177,957
65+	24,910	3.4	30,827	4.2	683,344	92.4	**250	**0.0	739,331
Total female	*56,379*	*2.9*	*70,425*	*3.7*	*1,788,906*	*93.3*	**1,578*	**0.1*	*1,917,288*

(continued)

Table A11 (continued): People with disability living in households, level of need for assistance with toileting, by age and sex, 2009

	Always/sometimes needs help or supervision		Does not need help but has difficulty		Has no difficulty		Does not use toilet		Persons
Age (years)	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**	**Number**
Persons									
0–39	53,689	5.9	18,648	2.1	828,294	91.5	4,920	0.5	905,550
40–64	25,213	1.7	51,921	3.5	1,397,607	94.8	–	–	1,474,740
65–84	31,988	2.7	38,644	3.3	1,112,904	93.9	**1,510	**0.1	1,185,047
85+	12,376	5.8	13,577	6.3	188,364	87.8	**250	**0.1	214,568
0–64	78,902	3.3	70,569	3.0	2,225,900	93.5	4,920	0.2	2,380,291
65+	44,364	3.2	52,221	3.7	1,301,269	93.0	*1,760	*0.1	1,399,614
Total persons	**123,267**	**3.3**	**122,790**	**3.2**	**3,527,169**	**93.3**	**6,680**	**0.2**	**3,779,905**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A12: People with disability living in cared accommodation, level of need for assistance with toileting, by age and sex, 2009

	Always/sometimes needs help or supervision		Does not need help but has difficulty		Has no difficulty		Does not use toilet		Persons
Age (years)	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**	**Number**
Male									
0–39	*454	*29.6	**107	**7.0	*842	*55.0	*128	*8.4	*1,531
40–64	3,741	51.8	*420	*5.8	2,773	38.4	*293	*4.1	7,227
65–84	15,935	69.8	1,117	4.9	4,468	19.6	1,307	5.7	22,827
85+	13,145	67.9	1,240	6.4	4,237	21.9	734	3.8	19,356
0–64	4,195	47.9	*527	*6.0	3,615	41.3	*421	*4.8	8,758
65+	29,080	68.9	2,358	5.6	8,705	20.6	2,040	4.8	42,183
Total male	*33,275*	*65.3*	*2,885*	*5.7*	*12,319*	*24.2*	*2,462*	*4.8*	*50,940*
Female									
0–39	*283	*49.7	**8	**1.3	*213	*37.4	**66	**11.6	*569
40–64	3,298	63.5	*159	*3.1	1,365	26.3	*368	*7.1	5,189
65–84	27,205	72.1	1,712	4.5	7,158	19.0	1,646	4.4	37,721
85+	46,476	73.3	3,502	5.5	10,683	16.8	2,768	4.4	63,429
0–64	3,581	62.2	*166	*2.9	1,577	27.4	*434	*7.5	5,758
65+	73,681	72.8	5,214	5.2	17,841	17.6	4,415	4.4	101,150
Total female	*77,262*	*72.3*	*5,380*	*5.0*	*19,418*	*18.2*	*4,849*	*4.5*	*106,908*

(continued)

Table A12 (continued): People with disability living in cared accommodation, level of need for assistance with toileting, by age and sex, 2009

	Always/sometimes needs help or supervision		Does not need help but has difficulty		Has no difficulty		Does not use toilet		Persons
Age (years)	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**	**Number**
Persons									
0–39	*737	*35.1	*114	*5.4	*1,055	*50.2	*194	*9.2	2,099
40–64	7,039	56.7	*579	*4.7	4,137	33.3	662	5.3	12,416
65–84	43,140	71.2	2,829	4.7	11,626	19.2	2,953	4.9	60,548
85+	59,621	72.0	4,743	5.7	14,919	18.0	3,502	4.2	82,785
0–64	7,776	53.6	*693	*4.8	5,192	35.8	856	5.9	14,516
65+	102,761	71.7	7,572	5.3	26,546	18.5	6,455	4.5	143,333
Total persons	**110,537**	**70.0**	**8,265**	**5.2**	**31,737**	**20.1**	**7,310**	**4.6**	**157,849**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A13: People with disability aged 10 and over living in households, types of aids used, by incontinence status, 2009

	Has severe incontinence		Does not have severe incontinence		Responses
	Number	**Per cent**	**Number**	**Per cent**	**Number**
Showering or bathing	69,896	40.6	255,967	7.4	325,863
Toileting	53,926	31.3	131,337	3.8	185,263
Managing incontinence	96,103	55.8	–	–	96,103
Dressing	17,482	10.2	48,061	1.4	65,543
Eating	10,300	6.0	18,000	0.5	28,299
Meal preparation	15,463	9.0	58,296	1.7	73,758
Getting into or out of a bed or chair	30,956	18.0	84,874	2.5	115,830
Moving about the house	53,045	30.8	196,903	5.7	249,947
Moving around places away from home	61,219	35.5	327,149	9.5	388,368
Communication	64,227	37.3	862,954	25.0	927,181
Managing health conditions with medical aids	75,637	43.9	783,886	22.7	859,523
Does not use aids or equipment	25,054	14.5	1,826,749	52.9	1,851,803
Total persons	**172,318**	**100.0**	**3,450,498**	**100.0**	**3,622,816**
Total number of responses[(a)]	**720,570**	**100.0**	**6,217,925**	**100.0**	**6,938,495**

(a) Respondents could respond 'yes' to more than one item, so components do not sum to column totals.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A14: People with disability aged 10 and over, living in households, use of toileting aids and whether needs additional aids to manage continence, 2009

	Male		Female		Persons	
	Number	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Whether uses toileting aid(s)						
Uses toileting aid(s)	68,872	3.9	116,391	6.3	185,263	5.1
Does not use toileting aid(s) but uses other aids	760,416	43.1	825,334	44.4	1,585,750	43.8
Does not use aid(s)	933,475	53.0	918,328	49.4	1,851,803	51.1
Whether additional aid(s) are needed to manage continence						
Needs additional aid(s)	*2,890	*0.2	*1,790	*0.1	4,680	*0.1
Does not need additional aids to help with managing incontinence, but needs other additional aids	99,649	5.7	116,499	6.3	216,149	6.0
Does not need any other additional aids	1,622,914	92.1	1,703,930	91.6	3,326,844	91.8
Don't know	37,309	2.1	37,834	2.0	75,143	2.1
Persons	**1,762,763**	**100.0**	**1,860,053**	**100.0**	**3,622,816**	**100.0**

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A15: Grouped main conditions reported by people who use continence aids, by residential status, 2009

	Number	Per cent of total population
Households		
Musculoskeletal	34,552	33.2
Neurological	14,977	14.4
All other conditions	14,200	13.7
Circulatory	6,251	6.0
Respiratory	*6,207	*6.0
Mental and behavioural (intellectual/learning)	*5,185	*5.0
Mental and behavioural (psychiatric)	*4,915	*4.7
Injury	*4,366	*4.2
Endocrine, nutritional and metabolic disorders	*3,907	*3.8
Dementia (including Alzheimer disease)	*2,734	*2.6
Digestive	*2,549	*2.5
Stroke	*2,436	*2.3
Neoplasms	*1,783	*1.7
Persons	**104,062**	**100.0**
Cared accommodation		
Dementia (including Alzheimer disease)	34,709	34.8
Musculoskeletal	13,829	13.9
Neurological	10,905	10.9
Stroke	9,614	9.6
All other conditions	7,890	7.9
Mental and behavioural (psychiatric)	7,647	7.7
Circulatory	5,500	5.5
Endocrine, nutritional and metabolic disorders	*2,564	*2.6
Respiratory	*2,450	*2.5
Injury	*1,718	*1.7
Neoplasms	*1,105	*1.1
Mental and behavioural (intellectual/learning)	*1,089	*1.1
Digestive	*666	*0.7
Persons	**99,685**	**100.0**

* Estimate has a relative standard error of 25–50% and should be used with caution.

Notes

1. 'Musculoskeletal' includes arthritis and related disorders, back problems (dorsopathies), osteoporosis, other soft tissue/muscle disorders (including rheumatism), repetitive strain injury/occupational overuse syndrome, and other diseases of the musculoskeletal system and connective tissue (ICD-10-AM Chapter 13).
2. 'Neurological' includes Parkinson disease, epilepsy, multiple sclerosis, cerebral palsy, migraine, paralysis, chronic/postviral fatigue syndrome and other diseases of the nervous system (ICD-10-AM Chapter 6).
3. 'Mental and behavioural (intellectual/learning)' includes intellectual and developmental disorders n.e.c., mental retardation/intellectual disability, autism and related disorders (including Rett syndrome and Asperger syndrome) and attention deficit hyperactivity disorder (ICD-10-AM Chapter 5).

(continued)

Table A15 (continued): Grouped main conditions reported by people who use continence aids, by residential status, 2009

Notes

4. 'Mental and behavioural (psychiatric)' includes depression/mood affective disorders (excluding postnatal depression), nervous tension/stress, schizophrenia, phobic and anxiety disorders, mental and behavioural disorders n.f.d. and other mental and behavioural disorders (ICD-10-AM Chapter 5).
5. 'Respiratory' includes emphysema, other diseases of the respiratory system, bronchitis/bronchiolitis, respiratory allergies (excluding allergic asthma) and asthma (ICD-10-AM Chapter 10).
6. 'Injury' includes head injury/acquired brain damage, arm/hand/shoulder damage from injury/accident, leg/knee/foot/hip damage from injury/accident, complications/consequences of surgery and medical care n.e.c. and other injury/poisoning and certain other consequences of external causes (ICD-10-AM Chapter 19).
7. 'Circulatory' includes heart disease, angina, hypertension (high blood pressure), myocardial infarction (heart attack), other heart diseases and other diseases of the circulatory system (ICD-10-AM Chapter 9).
8. 'Endocrine, nutritional and metabolic disorders' includes disorders of the thyroid gland, diabetes, and other endocrine/nutritional and metabolic disorders (ICD-10-AM Chapter 4).
9. 'Stroke' includes stroke only.
10. 'Dementia' includes Alzheimer's disease and dementia (ICD-10-AM Chapter 5).
11. 'All other conditions' includes certain infectious and parasitic diseases, diseases of the blood and blood forming organs and certain disorders involving the immune system, high cholesterol, speech impediment, retinal disorders/defects, glaucoma, sight loss, other diseases of the eye and adnexa, diseases of the middle ear and mastoid, diseases of the inner ear (except noise induced deafness), tinnitus, deafness/hearing loss, deafness/hearing loss (noise induced), deafness/hearing loss (congenital), other diseases of the ear and mastoid processes, skin allergies (dermatitis and eczema), other diseases of the skin and subcutaneous tissue, kidney and urinary system (bladder) disorders (except incontinence), menopause disorders, other diseases of the genitourinary system, certain conditions originating in the perinatal period, congenital malformations, deformations, and chromosomal abnormalities, breathing difficulties/shortness of breath, pain n.f.d, unspecified speech difficulties, other symptoms/signs and abnormal clinical and laboratory findings n.e.c., restriction in physical activity or physical work and other long-term conditions (all other ICD-10-AM chapters).

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A16: People who need assistance with managing their bladder or bowel control, living in households: extent to which need for core activity assistance is met, 2009

	0–64 years		65+ years		Total	
	Number	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Need fully met for core activities	46,397	58.5	44,792	75.1	91,189	65.6
Need partly met for core activities	28,811	36.3	13,145	22.0	41,956	30.2
Need not met at all for core activities	*4,162	*5.2	*1,708	*2.9	5,870	4.2
Total	**79,369**	**100.0**	**59,645**	**100.0**	**139,014**	**100.0**

* Estimate has a relative standard error of 25–50% and should be used with caution.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A17: Primary carers, level of care provided, by whether usually assisted with managing incontinence, 2009

	Usually assisted with managing incontinence		Does not usually assisted with managing incontinence		Persons	
	Number	Per cent	Number	Per cent	Number	Per cent
Average number of hours spent caring each week						
0–19	11,079	15.2	321,077	47.7	332,157	44.5
20–29	*4,381	*6.0	87,341	13.0	91,722	12.3
30–39	*3,014	*4.1	39,741	5.9	42,755	5.7
40+	53,189	73.0	209,753	31.1	262,942	35.2
Don't know	**1,193	**1.6	15,575	2.3	16,768	2.2
Number of tasks for which main recipient of care requires assistance due to disability or age						
None	9,532	13.1	135,120	20.1	144,652	19.4
1 to 4	*3,214	*4.4	156,861	23.3	160,075	21.4
5 to 9	11,745	16.1	250,790	37.2	262,535	35.2
10 to 14	28,386	39.0	107,484	16.0	135,870	18.2
15 or more	19,545	26.8	20,030	3.0	39,575	5.3
Not stated	**434	**0.6	*3,202	*0.5	*3,637	*0.5
Total primary carers	**72,856**	**100.0**	**673,488**	**100.0**	**746,344**	**100.0**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Note: Components may not add to total due to rounding.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A18: Primary carers who live with their main care recipient, whether main care recipient able to care for self at home if left on own for a few hours, by whether assists with managing incontinence, 2009

	Usually assists with managing incontinence		Does not usually assist with managing incontinence		Persons
Could manage without difficulty	16,728	26.6	293,577	56.9	310,305
Could manage with difficulty	*3,584	*5.7	55,488	10.8	59,071
Could not manage	25,469	40.5	81,207	15.7	106,676
Not known	17,109	27.2	85,872	16.6	102,981
Persons	**62,890**	**100.0**	**516,144**	**100.0**	**579,033**

* Estimate has a relative standard error of 25–50% and should be used with caution.

Note: Components may not add to total due to rounding.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A19: Primary carers, type of task primary carer assisted recipient of care with, by whether assisted with managing incontinence, 2009

	Usually assists with managing incontinence		Usually does not assist with managing incontinence		Persons
	Number	Per cent	Number	Per cent	Number
Bathing or showering					
Usually assists with bathing or showering	52,413	71.9	215,373	32.0	267,786
Does not usually assist with bathing or showering	20,443	28.1	458,115	68.0	478,558
Getting into or out of a bed or chair					
Usually assists with getting into or out of a bed or chair	40,823	56.0	190,272	28.3	231,095
Does not usually assist with getting into or out of a bed or chair	32,033	44.0	483,215	71.7	515,248
Eating or feeding					
Usually assists with eating or feeding	47,549	65.3	126,063	18.7	173,612
Does not usually assist with eating or feeding	25,307	34.7	547,424	81.3	572,732
Cognitive or emotional tasks					
Usually assists with cognitive or emotional tasks	63,935	87.8	551,111	81.8	615,046
Does not usually assist with cognitive or emotional tasks	*2,521	*3.5	56,307	8.4	58,828
Not stated	*6,399	*8.8	66,070	9.8	72,470
Mobility tasks					
Usually assist with mobility tasks	59,065	81.1	489,819	72.7	548,884
Does not usually assist with mobility tasks	13,791	18.9	183,668	27.3	197,459
Communication tasks					
Usually assist with communication tasks	46,751	64.2	293,198	43.5	339,949
Does not usually assist with communication tasks	26,105	35.8	380,289	56.5	406,395
Persons	**72,856**	**100.0**	**673,488**	**100.0**	**746,344**

* Estimate has a relative standard error of 25–50% and should be used with caution.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A20: Primary carers of working age (15–64), labour force status, by whether assists with managing someone else's bladder or bowel control, 2009

	Usually assists with managing incontinence		Does not usually assist with managing incontinence		Persons
	Number	**Per cent**	**Number**	**Per cent**	**Number**
Employed working full time	*8,377	*15.2	132,929	26.7	141,306
Employed working part time	15,457	28.1	128,519	25.9	143,976
Unemployed looking for work	**493	**0.9	14,065	2.8	14,559
Not in the labour force	30,639	55.7	221,537	44.6	252,176
Labour force participation rate (%)	–	*44.3*	–	*55.4*	–
Total primary carers of working age	**54,966**	**100.0**	**497,050**	**100.0**	**552,016**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Note: Components may not add to total due to rounding.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A21: Primary carers, participation and financial situation, by whether assists with managing someone else's bladder or bowel control, 2009

	Usually assists with managing incontinence		Does not usually assist with managing incontinence		Persons
	Number	**Per cent**	**Number**	**Per cent**	**Number**
Participation in social or community activities in the last 12 months without the recipient of care					
Has participated	25,896	35.5	197,858	29.4	223,754
Has not participated	10,512	14.4	87,025	12.9	97,536
Not applicable[(a)]	36,448	50.0	388,605	57.7	425,053
Whether primary carer has difficulty meeting everyday costs as a result of caring role					
Has difficulty meeting everyday living costs	29,227	40.1	190,481	28.3	219,708
Does not have difficulty meeting everyday living costs	15,905	21.8	102,855	15.3	118,759
Not stated	6,913	9.5	66,369	9.9	73,282
Not applicable[(b)]	20,811	28.6	313,783	46.6	334,594
Main effect of caring role on primary carer's financial situation					
Income not affected	18,981	26.1	293,226	43.5	312,207
Income has increased	*1,830	*2.5	20,557	3.1	22,387
Income has decreased	20,213	27.7	139,232	20.7	159,445
Has extra expenses	24,919	34.2	153,548	22.8	178,467
Not stated	6,913	19.5	66,925	9.9	73,838
Total primary carers	**72,856**	**100.0**	**673,488**	**100.0**	**746,344**

* Estimate has a relative standard error of 25–50% and should be used with caution.

(a) Only primary carers aged 60 and under without a disability were asked this question.

(b) Only primary carers whose financial situation had been affected by their caring role were asked this question.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A22: Primary carers, effect of caring role on sleep, by whether assisted with managing incontinence, 2009

	Usually assists with managing incontinence		Does not usually assist with managing incontinence		Persons
	Number	Per cent	Number	Per cent	Number
Whether primary carer's sleep is interrupted frequently or occasionally due to caring role					
Sleep interrupted frequently	30,750	42.2	131,282	19.5	162,032
Sleep interrupted occasionally	19,845	27.2	154,415	22.9	174,260
Sleep is not interrupted	15,862	21.8	322,458	47.9	338,320
Sleep interrupted but frequency not stated or not stated	6,399	8.8	65,332	9.7	71,732
Whether primary carer's interrupted sleep interferes with normal daily activities					
Sleep interrupted frequently interferes with normal daily activities	24,433	33.5	101,093	15.0	125,526
Sleep interrupted frequently does not interfere with normal daily activities	6,317	8.7	28,895	4.3	35,213
Sleep interrupted frequently but interference with normal daily activities not stated	–	–	**1,294	**0.2	**1,294
Sleep interrupted occasionally interferes with normal daily activities	9,930	13.6	78,247	11.6	88,177
Sleep interrupted occasionally does not interfere with normal daily activities	9,915	13.6	76,168	11.3	86,083
Sleep interrupted but frequency or interference not stated or Not stated	*6,399	*8.8	65,332	9.7	71,732
Sleep is not interrupted	15,862	21.8	322,458	47.9	338,320
Persons	**72,856**	**100.0**	**673,488**	**100.0**	**746,344**

* Estimate has a relative standard error of 25–50% and should be used with caution.

** Subject to sampling variability too high for practical purposes (that is, relative standard error greater than 50%).

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A23: Primary carers, main unmet need, by whether assisted with managing incontinence, 2009

	Usually assists with managing incontinence		Does not usually assist with managing incontinence		Persons
	Number	Per cent	Number	Per cent	Number
More respite care	10,541	14.5	27,175	4.0	37,715
More financial assistance	11,628	16.0	77,207	11.5	88,836
More physical assistance	*5,540	*7.6	26,004	3.9	31,544
More emotional support	*2,962	*4.1	25,697	3.8	28,659
An improvement in carer's own health	*2,528	*3.5	20,276	3.0	22,803
More aids/equipment/courses/training	*2,017	*2.8	22,832	3.4	24,849
None of the above	–	–	9,965	1.5	9,965
Source of support not answered	11,359	15.6	106,220	15.8	117,580
No additional support required	26,281	36.1	358,112	53.2	384,393
Total	**72,856**	**100.0**	**673,488**	**100.0**	**746,344**

* Estimate has a relative standard error of 25–50% and should be used with caution.

Source: AIHW analysis of the 2009 ABS SDAC CURF.

Table A24: Source of expenditure on continence aids, 2004–05 to 2009–10

	Supermarket expenditure	Continence Aids Assistance Scheme	Consumer out-of-pocket
	$ million	$ million	$ million
2004–05	33.3	9.4	23.9
2005–06	39.6	11.2	28.4
2006–07	43.9	11.2	32.7
2007–08	49.9	20.1	29.8
2008–09	54	31.6	22.4
2009–10	71.5	41.4	30.1

Sources: AIHW analysis of DoHA unpublished data and Gloria 2004, 2005, 2006, 2007, 2008, 2009, 2010.

Glossary

Activities and Participation: A classification within the International Classification of Functioning, Disability and Health (ICF) (WHO 2001): 'Activity is the execution of a task or action by an individual. Participation is involvement in a life situation' (p14). For more information, see Chapter 7.

activities of daily living: Self-care, mobility and communication. These correspond to the three areas of core activity limitation in the 2009 Survey of Disability, Ageing and Carers (ABS 2010).

anal incontinence: Involuntary loss of fecal material and/or flatus (Abrams et al. 2006). For more information, see Chapter 2.

Body Functions and Structures: A classification within the ICF (WHO 2001): 'Body functions are the physiological functions of body systems (including psychological functions)' and 'Body structures are anatomical parts of the body such as organs, limbs and their components' (p12). For more information, see Chapter 1.

body mass index (BMI): BMI is a ratio of weight to height, and is a guide to whether a person is a healthy weight or not (WHO 2000). For information, see Box 3.4.

burden of disease: Burden of disease is a term used to quantify the effect of a health issue. It uses measures such as financial cost, mortality, morbidity (the effect of ill health) and years affected by a condition. For more information, see Chapter 6. See also **Disability adjusted life year (DALY)**, **Years of life lost (YLL)** and **Years of life lost due to disability (YLD)**.

cared accommodation: Facilities such as hospitals and nursing homes; excludes correctional institutions. In the 2009 SDAC, people were considered to be living in cared accommodation if they lived in such facilities for 3 months or more.

comorbid conditions: The terms 'comorbidity' or 'comorbid conditions' refer to the presence of more than one medical condition in an individual. For more information, see Box 3.3.

continence and toileting aids: Aids and equipment used by people with disability to assist them with managing incontinence or toileting, not including help provided by another person or an organisation. For more information, see Chapter 4 and Box 4.1.

core activity limitations: The SDAC defines core activities as communication, mobility and self-care. For more information, see Box 4.3.

disability: The 2009 SDAC asked a series of questions to identify people with disability. A person had a disability if they experienced any one of 17 limitations, restrictions or impairments and a restriction in everyday activities. For this list, and further information, see Box 2.1.

disability adjusted life year (DALY): The DALY describes the amount of time lost due to both fatal and non-fatal events—by combining the years of life lost (YLL) and years of 'healthy' life lost due to disability (YLD). For more information, see Chapter 6.

Environmental Factors: A classification within the ICF (WHO 2001): 'Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives' (p12). For more information, see Chapter 7.

fecal incontinence: Any involuntary loss of fecal material (Abrams et al. 2006). For more information, see Chapter 2.

flatus incontinence: Any involuntary loss of gas (flatus). See also **anal incontinence**.

functional incontinence: Physical or other limitation that prevents a person from being able to access the toilet, apart from stress or urge incontinence.

incidence: The number of new cases of an illness or disease, during a given period in a specified population. For more information, see Box 3.1.

mixed incontinence: Usually only used with reference to urinary incontinence: the complaint of involuntary leakage associated with urgency and also with exertion, effort, sneezing or coughing. For more information, see Chapter 2.

prevalence: The number of cases of a disease or condition in a population at a given time. In Chapter 4, the prevalence of severe incontinence for the Australian resident population was presented according to the 2009 SDAC, for that year.

primary carer: According to the 2009 SDAC, a primary carer is a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least 6 months and be provided for one or more of the core activities (communication, mobility and self-care). In the SDAC, primary carers only included persons aged 15 and over for whom a personal interview was conducted. Persons aged 15 to 17 were only interviewed personally if parental permission was granted.

self-care assistance: In the 2009 SDAC, self-care assistance refers to help or supervision with bathing/showering, dressing, eating, toileting or managing bladder or bowel control. For more information, see Box 2.1.

severe incontinence: For the purposes of this report, people with disability were identified as having severe incontinence if they:

- answered 'yes' to having difficulty with controlling bladder or bowel functions and 'yes' to ever needing help with managing this difficulty (either always or sometimes needing help)

  and/or

- answered 'yes' to using continence aid(s).

stoma appliances: A stoma is an artificial opening in the bowel or urinary system that has been deliberately made to divert the flow of faeces or urine. For more information, see Chapter 6.

stress incontinence: Usually only used with reference to urinary incontinence: the complaint of involuntary leakage on effort or exertion, or on sneezing or coughing. For more information, see Chapter 2.

toileting: Needing help to manage toileting is different to needing help with managing bladder or bowel control. Toileting requires the physical and intellectual capacity to carry out the steps needed to use the toilet, including knowing where the toilet is, removing the necessary clothing, using the toilet appropriately and getting dressed again. For more information, see Chapter 4.

urge incontinence: Usually only used with reference to urinary incontinence: the complaint of involuntary leakage accompanied by, or immediately preceded by, urgency.

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