1 Introduction

1.1 This report

This report is the outcome of a project undertaken by the Australian Institute of Health and Welfare (AIHW) on the consistency and comparability of dependency measures across aged and community care programs. The Australian Government Department of Health and Ageing requested the AIHW undertake this project to:

- assess the comparability of data elements related to measuring dependency/need for assistance of clients across three program areas: Home and Community Care (HACC), Aged Care Assessment Program (ACAP) and residential aged care program areas; and
- identify any recommended modifications of measures of dependency to improve comparability across programs.

This project was one of several undertaken by AIHW over recent years under a Memorandum of Understanding (MOU) between the Institute and the Australian Government Department of Health and Ageing to improve the availability, consistency and relevance of national aged and community care information. Ensuring consistency with national and international data standards is an overarching goal of all projects under the MOU, in particular with the National Community Services Data Dictionary (NCSDD), the National Health Data Dictionary (NHDD) and relevant standards developed by the Australian Bureau of Statistics (ABS), and the International Classification of Functioning, Disability and Health (ICF).

In this report, dependency measures used in aged and community care programs are compared with each other and with national and international standards. Quality data that are consistent with national standards wherever possible and that allow for valid comparison between programs, jurisdictions or planning regions are essential for government and non-government agencies in the health and community services sectors for policy development, service planning and monitoring. The development of nationally consistent data was put forward as a major objective by all signatories to the National Community Services Information Agreement (1997). The National Community Services Information Development Plan (SCCSISA 1999) formally identified the need for quality national community services data, recognising that data consistency will improve the quality of data by reducing the need to map, re-enter and translate data, and will reduce the cost of developing, collecting, aggregating and analysing data.

The aims of the data collections and, in particular, of the measurement of dependency in the aged and community care programs are diverse. Dependency information that is available for national analysis is a by-product of administrative processes relevant to each program, where the primary purpose of data collection in each program is to support service delivery. Variations in data are often related to variations in the nature, objectives and target groups of programs. For example in some programs, information on the level of dependency assists with determining eligibility for aged care services by individuals. In other cases, such as the Residential Classification Scale (RCS), the information is used to determine the level of funding paid to the residential aged care facility for the care of each resident.

As a result of this diversity in the objectives and context of each data collection, large differences exist between the instruments used to measure dependency in aged and community care programs. As a consequence, it is difficult to make comparisons of data on client dependency across programs. However, where variations exist in the reporting of data, it may be feasible to map the data to a common level that is meaningful across all aged and community care programs. This is the approach that has been used in this report. Where data items cannot be mapped, recommendations have been made with regard to changes to the data collections which should be considered to allow mapping of the data and to improve data comparability.

While this project originally aimed to compare dependency items in two aged and community care programs (HACC and ACAP) and the residential aged care program (RCS), the emphasis was shifted during the life of the project. Plans of a likely review of the RCS meant that detailed description of a comparison with the current RCS was not desirable. It is recommended that the review of the RCS consider the need to improve consistency with aged and community care data, and consider the recommendations of this report with regard to improving information on the dependency of aged and community care clients.

The detailed mapping and comparison described in Chapter 5 still includes dependency items in the ACAP and HACC programs, but also includes items from the CACP program. These three programs are all partly or fully funded by the Australian government, and all provide services to frail or disabled (older) people living in the community, with emphasis on enabling their clients to remain living in their own home where possible.

1.2 The value of comparable data

Data that are consistent with national standards and that allow meaningful and valid comparisons to be made across aged and community care programs are essential to support policy development, program planning and performance monitoring. Consistent data on dependency would provide answers to general questions about dependency in community care clients, allow comparisons with population data, and allow a range of more complex analyses and comparisons. In particular, data that are sufficiently consistent could:

- allow comparison of data across programs: this would potentially answer questions such as 'Are the client groups of each program different in terms of type and level of dependency?', 'Is there any overlap or duplication?';
- allow comparison of trends over time in dependency levels across aged care programs;
- allow comparison with population data: this is an important aspect of program performance monitoring, and would allow the application of performance indicators across programs. Improved information on the number of people with a severe or profound core activity restriction who receive services in each program could be compared with ABS data on the population with a severe or profound core activity restriction[1]. Questions to be answered may include ones about access and equity, e.g. 'Are the people in need of assistance receiving it?';
- improve the information available across aged care programs on clients' need for assistance with particular activities, such as managing incontinence;

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1 Someone with a severe or profound core activity restriction is defined as sometimes or always needing assistance from another person with the activities of self-care, mobility or communication.

- allow comparisons of other activity groupings of, for example, Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) (see Section 4.4);
- allow the construction and comparison of a summary measure on dependency, such as previously carried out between the CACP data collection and the Community Options data collection in the publication *Community Aged Care Packages: How Do They Compare?* (AIHW 1997b:40); and
- allow a more complex range of analyses to be undertaken, when used in conjunction with consistent data on key environmental and personal factors, such as the presence of an informal carer.

1.3 International and national standards

The international and national standards used in assessing consistency during this project are the ICF, the NCSDD Version 2 and the NHDD Version 12. The ICF has provided a framework for this project, with its groupings of health-related components/domains, and a classification of activities. More discussion of the ICF is provided under Section 1.5 of this chapter, and a mapping of aged and community care items to the relevant ICF codes is presented in Appendix A.

The NCSDD and the NHDD have been endorsed by the National Community Services Information Management Group (NCSIMG) or the National Health Information Management Group (NHIMG) and agreed for use in all national community services or health information development projects. Under the National Community Services Information Agreement, the NCSDD is the authoritative source of community services data definitions where national consistency is required or desired (AIHW 2000a:1). Similarly, the NHDD is the authoritative source of health data definitions where national consistency is required under the National Health Information Agreement (AIHW 2001:xxiii). Efforts have been made, and are continuing, to ensure the alignment of these two data dictionaries with major classifications such as the ICF. Trial data elements based on the draft International Classification of Functioning, Disability and Health–2 (ICIDH-2) are included in the NCSDD Version 2, and an extended set of data elements based on the ICF will be included in the NCSDD Version 3.

In assessing for consistency, the ABS Survey of Disability, Ageing and Carers 1998 has also been used as a basis for comparison in this project. It provides more detail than the NCSDD and the NHDD, enabling comparison of specific activities such as transferring or dressing. Consistency with the ABS survey will allow comparability of national aged and community care program data with this main source of population data relevant to the aged and community care target population. Both NCSIMG and NHIMG endorse the use of Australian Bureau of Statistics standards where relevant.

1.3.1 National Community Services Information Model Version 1

The National Community Services Information Model Version 1.0 was developed by the Australian Institute of Health and Welfare during 1997, in consultation with the National Community Services Information Model Working Group. The Working Group was a subset of the National Community Services Data Committee (NCSDC), which is, in turn, a subcommittee of the National Community Services Information Management Group (NCSIMG). Membership of the NCSIMG includes representatives of all signatories to the

National Community Services Information Agreement, including Australian government, state and territory government departments responsible for community services, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare.

The NCSDC was established primarily to develop and maintain the National Community Services Data Dictionary as the repository of nationally endorsed data definitions for use in the community services field across Australia. The NCSDC has a coordinating role to ensure national consistency and standards in quality control. The development of the National Community Services Information Model was seen by the NCSDC as the first step in improving the quality and consistency of national community services information.

The National Community Services Information Model (NCSIM) Version 1.0 (Modified) is reproduced in Appendix C (also published in the NCSDD Version 2). Two entities, Care plan and Business factors, from the National Health Information Model (NHIM) Version 2.0 (draft) have been included to provide a more comprehensive framework. Figure 2 in Section 1.5 provides an example of a mapping of dependency-related aged and community care data items to the NCSIM.

1.4 Dependency and its prevalence in the aged

Dependency can be defined as a state in which an individual is reliant on others for assistance in meeting recognised needs. This assistance may be provided by family, friends and neighbours, or it may be formal assistance provided by government or private agencies (Rickwood 1994). Defined in this way, dependence on aids and equipment alone is specifically excluded, although it is acknowledged that the presence or absence of aids and equipment may be a significant environment factor affecting an individual's performance of activities.

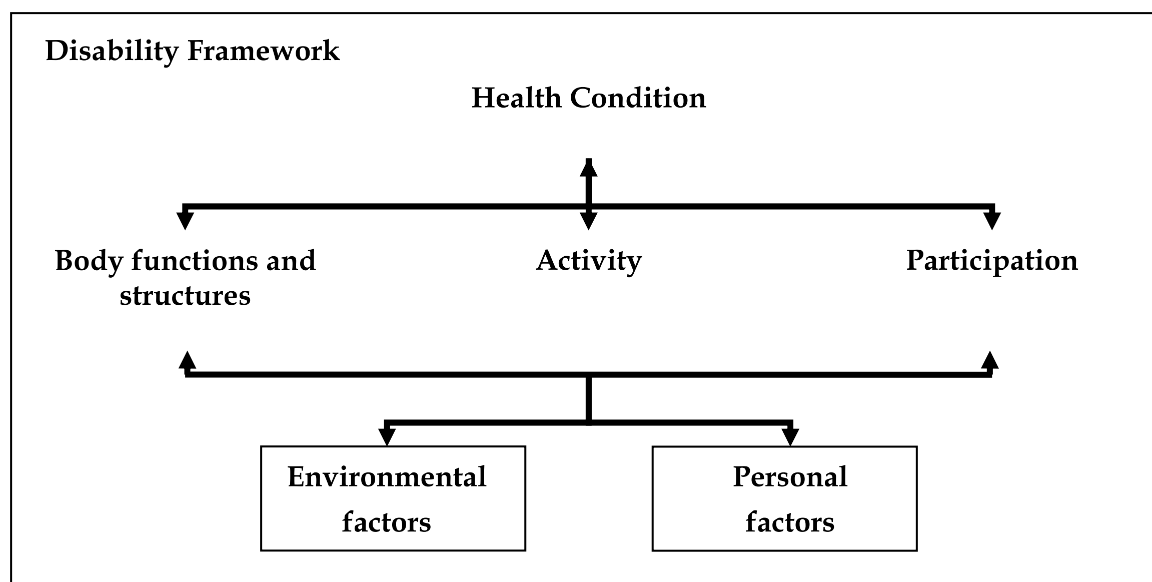
While people can be dependent at any age, it is much more common in the very young and older age groups. Since 1981, the Australian Bureau of Statistics has conducted the Survey of Disability, Ageing and Carers (conducted in 1981, 1988, 1993 and 1998). These surveys provide self-reported information about dependency in the older population, including people living in the community and those accommodated in care facilities. According to the 1998 survey, which provides the most recent data, one in five people aged 65 and over reported a profound or severe core activity restriction. Someone with a profound or severe core activity restriction is defined by the ABS as needing assistance from another person, sometimes or always, with the activities of mobility, self-care or communication. It is estimated that, in 1998 in Australia, out of approximately 2¼ million aged persons, nearly ½ million people were dependent on others for help with fundamental activities of daily living such as bathing, eating, walking and communicating (AIHW 1999). As well as this group of aged persons, many younger people with a disability are dependent on others. The vast majority of assistance to persons with a severe or profound core activity restriction is provided by informal carers. Formal services, such as those provided by the HACC and CACP programs to people living in the community, and care provided in residential aged care facilities, play an important role in meeting the needs of dependent persons.

1.5 ICF and NCSIM

The concept of dependency is closely related to the concepts of 'functioning' and 'disability'. In the International Classification of Functioning, Disability and Health (ICF), a person's functioning and disability is described as a dynamic interaction between health conditions and contextual factors, where contextual factors include personal and environmental factors. The environmental factors are portrayed as the physical, social and attitudinal world, which can have a facilitating or hindering impact on the person's functioning (WHO 2001).

The model below, Figure 1, as presented in the ICF, aims to assist in understanding the interaction between these components. It presents disability as a multi-dimensional experience for people, in terms of body functions and structures, activities they carry out, their participation in a range of life areas, and factors in the environment in which they live and conduct their lives. As pointed out in the ICF, any diagram depicting such a complex concept is likely to be incomplete and prone to misrepresentation (WHO 2001:18). However, this model may assist in visualising the dynamic interaction between the domains related to human health and functioning. The domains presented in bold text are those included in the scope of the ICF as a classification. Health conditions are not included in the ICF, but are classified in the International Classification of Diseases and related problems (ICD). Personal factors are also not classified in the ICF because of the large social and cultural variation associated with them. Personal factors include attributes of the individual such as gender, ethnicity and coping styles (AIHW 2000b, WHO 2001).

Figure 1: Interaction between the components of the ICF



In order to determine what information should be included in the scope of this project, a number of data elements (a data element is a unit of data) and instruments across the aged and community care collections were considered. Some of these provide information about the context or environment of the client (Environmental and Personal factors), while others relate to the Activity/Participation domains, and are a more direct 'measure' of the person's (dis-)ability (see Figure 2). Contextual data elements include Carer availability (HACC and ACAP) or Living arrangements (HACC and ACAP). Other data elements that are related to

dependency but that do not necessarily indicate whether a person is dependent or has a disability include Health condition (ACAP) and Dementia status (ACAP). Data elements/instruments that provide a picture of the person's ability and need for assistance, without consideration of his or her context or environment (as far as possible), include (Core) Activity limitations (CACP), Activity areas (NCSDD Version 2), Domestic or Behavioural functioning (HACC). These more direct 'measurements' are the focus of this report.

While these more direct measures are related to the domains of Activity and Participation in the ICF, within the aged and community care data collections these measures are often expressed in terms of the need for assistance. The ICF, as a classification of life areas or activities in which a person may be involved, suggests the use of qualifiers for performance and for capacity in an area,[2] and these qualifiers could be applied to take into consideration the use of aids and equipment and the need for personal assistance. However, performance and capacity qualifiers cannot be uniformly applied without assessment procedures being in place. The ICF flags the need for the development of such assessment procedures and/or calibration (WHO 2001:124).

The National Community Services Information Model Version 1.0 (NCSIM) (see Appendix C) also provides a framework for considering the factors which impact on a person's functioning, which is based on the draft ICIDH-2.

The model entity Person participation/independence is defined to be the person's participation/independence in relation to personal maintenance, mobility, exchange of information, social relationships, work, education, leisure, spirituality, economic life and civic and community life. The NCSIM provides the framework for the NCSDD. In the NCSDD, data elements relating to Activity and Participation describe this entity, and include elements which define areas of activity and areas of participation, as well as data elements which describe the person's level of difficulty and need for assistance in undertaking an activity.

Revisions of these data elements to ensure consistency with the ICF, now endorsed by WHO, will be included in Version 3 of the NCSDD (due for release early 2004). Inclusion of these revised data elements in Version 3 will be another step in improving consistency of national community services data, and will provide those responsible for the development and maintenance of national data collections with national standards that are consistent with both the ICF and Australian population data.[3]

It is worth noting here that the Commonwealth State/Territory Disability Agreement National Minimum Dataset (CSTDA NMDS)[4] includes the data element 'Activities and participation—support needs', which is recorded and reported in conjunction with the data element 'Activities and participation areas'. Together, these two data elements offer a framework for reporting support needs that is consistent with the ICF as well as the ABS Survey of Disability, Ageing and Carers (and thus with Australian population data) (AIHW 2002c).

Figure 2 provides a mapping of one key source of dependency-related data (ACAP MDS V2.0) to both the ICF and the NCSIM.

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2 The ICF uses the concepts *performance* and *capacity* to distinguish between a person's ability to carry out a task in his or her current or usual environment and the person's ability in a standardised environment. See Section 1.7 for further explanation of these concepts.

3 The ABS Survey of Disability, Ageing and Carers, to be run in 2004, will include questions based on the ICF.

4 The CSDA MDS Version 2 was implemented on 1 October 2002.

Figure 2: Mapping of data elements in ACAP MDS V2.0 to the ICF Disability Framework and NCSIM V1.0

ICF Disability Framework		Data elements ACAP MDS V2.0		NCSIM Version 1
Personal factors	←	Date of birth Sex Indigenous status Country of birth Main language other than English spoken at home Proficiency in spoken English	→	*Person characteristics* Demographic characteristic Socio-cultural characteristic
Health condition	←	Health condition	→	*Party characteristics* State of wellbeing
Body functions & structures (and impairment)	←	Body function impairments	→	*Person characteristics* Functional characteristic
Activity (and limitations) Participation (and restrictions)	←	Activity limitations	→	*Person participation/ independence*
Environmental factors	←	Current assistance with activities Respite care use	→	
	←	Carer co-residency status Accommodation setting—usual Living arrangements	→	*Person characteristics* Accommodation/living characteristic
	←	Carer availability Relationship of carer to care recipient	→	*Person role* *Carer role*

1.6 Environmental factors and health condition

Direct measures of dependency may not in themselves provide an adequate measure of a person's need for assistance. A range of other factors exist which may impact on a person's functioning and their need for assistance. These factors are classified as contextual factors, which include environmental and personal factors, within the ICF framework (see Figure 1).

Environmental factors are defined as the physical, social and attitudinal environment in which people live and conduct their lives (WHO 2001:171), and they may be either facilitators or barriers to a person's functioning and participation. Recording environmental factors within the framework allows a more complete description of the person's functioning.

Data elements describing environmental factors are included in each of the community aged care programs considered in this report, as well as the ABS Survey, the NCSDD and the NHDD, and these data elements are listed in Table 1.

Table 1: Environmental factors data items

ACAP MDS	Accommodation setting (usual) Living arrangements Carer availability Relationship of carer to care recipient Carer co-residency status Government program support at assessment Respite care use Current assistance with activities Source of current assistance
HACC MDS	Living arrangements Accommodation setting Carer—existence of Carer residency status Relationship of carer to care recipient
CACP census data collection	Carer availability Carer co-residency status Relationship of carer to care recipient
ABS Survey of Disability, Ageing and Carers	Dwelling information Assistance provided by carer Carer status Relationship of carer
NHDD	Carer availability
NCSDD	Carer co-residency Living arrangements Residential setting

An AIHW working paper published in 2002, *Comparability and Consistency of Community Care Metadata*, provides an assessment of comparability of data items between four aged and community care programs: HACC, ACAP, CACP and NRCP (National Respite for Carers Program). That paper includes an assessment of the environmental factors listed in Table 1, and the results show that there is a high degree of consistency and comparability between data on environmental factors collected in the three aged and community care programs under scrutiny in this report (Jeffery and Ryan 2002).

An individual's functioning, as portrayed in the ICF diagram (Figure 1), is an interaction between the person's health condition and contextual factors (environmental and personal

factors). Functioning should therefore not be regarded as separate from health condition and contextual factors. To describe the full health experience, all these components are important.

Combining consistent aged and community care data on environmental factors and health condition with data on clients' dependency can provide a fuller picture about clients' circumstances, including the need for assistance and the need for formal services. Figure 5 in Section 4.1 provides just one example of how data may be combined and used to provide information beyond clients' dependency in isolation.

1.7 Performance and capacity

The ICF uses the concepts *performance* and *capacity* to distinguish between a person's ability to carry out a task in his or her current or usual environment and the person's ability in a standardised environment. The standardised environment could be seen as an 'ideal' or optimum environment, in which the person's full ability can be assessed. Or, in other words, the concept 'capacity' relates to the person's highest probable level of functioning, without the interference of impeding factors that may exist in the usual environment. This ideal environment may be an actual environment used for assessment of the person's functional ability, or it could be an assumed environment that is thought to assist in improving a person's level of functioning (AIHW 2003c).

Dependency information collected in the ACAP, HACC and CACP programs, and that collected by the ABS, relates mainly to performance, i.e. what an individual is able to do in the current or usual environment. However, the ACAP and CACP programs differ from the HACC Functional Dependency Instruments and the ABS survey in that they bring into their collection a measure of capacity. In these two programs, if the client's need for assistance could be met by their independent use of aids and equipment, they are recorded as not needing assistance from another person, even if in the current environment the client does not (yet) have access to such aids or equipment. This has obvious implications for comparability between these two programs and the HACC program, but is an issue not likely to be easily resolved, as each program's approach to client assessment is directly related to the purpose of that program.

2 Dependency in aged and community care programs

2.1 Aged and community care programs

A range of Australian and state/territory government programs provide services to older Australians in need of assistance.

The Aged Care Assessment Program (ACAP) is a Australian government-funded program, which is designed to 'comprehensively assess the needs of frail older people and facilitate access to available care services appropriate to their needs'. State and territory governments also contribute significant resources to this program. Following a comprehensive assessment, an Aged Care Assessment Team may approve a person as eligible for entry to a residential aged care service, receipt of a Community Aged Care Package or receipt of Flexible Care (e.g. an Extended Aged Care at Home package) (AIHW 2002a).

The Community Aged Care Package (CACP) Program is also Australian government-funded, and was established in 1992. It provides assistance to enable frail or disabled older people with complex care needs to continue living in the community. Younger people with disabilities may also access a care package where there are no appropriate care options available in an area. The CACP Program has grown rapidly and by 30 June 2002 more than 26,000 packages were operational (AIHW 2003a).

The Home and Community Care (HACC) Program is jointly funded by the Australian government and the state and territory governments. The program provides services to frail or disabled older people and their carers (approximately 80% of the HACC client population) and to younger people (aged under 70) with a disability and their carers (the remaining 20%).

Residential aged care in Australia is Australian government-funded and consists of close to 3,000 residential aged care services (as at 30 June 2002), providing over 146,000 places (AIHW 2003b). The structure of aged care services was changed in October 1997, amalgamating nursing homes and hostels into one system. This re-structure aimed to facilitate the ability of residents to 'age in place', allowing low care residents to stay in the same facility even when their dependency levels increase.

2.2 Measurement of dependency in aged and community care programs

There have been some major developments in the area of data development and collection in each of the above-mentioned programs in recent years.

ACAP

From 1999 to 2001 a review of the ACAP Minimum Data Set (MDS) was undertaken by the AIHW in collaboration with the Aged Care Assessment Program Data Working Group (including Australian government and state/territory representatives), resulting in

Version 2.0 of the ACAP MDS and the production of the Aged Care Assessment Program Data Dictionary Version 1.0. The inclusion of the data element *Activity limitations* means that national information on ACAP clients' need for assistance with self-care, mobility and communication will be included in future data collections. National collection and reporting of the ACAP MDS Version 2.0 commenced in January 2003 (AIHW 2002a).

CACP

Another recent project, also undertaken by the AIHW in collaboration with DoHA, involved the identification of information needs in the CACP Program, and the development of the CACP Data Dictionary Version 1.0. This data dictionary also includes a data element, *Core activity limitations,* that measures the need for assistance with key activities of daily living. While, as in the ACAP Data Dictionary, this data element records information on self-care, mobility and communication, this information is recorded at a more detailed level, as it includes information on individual activities such as eating, dressing, walking (AIHW final draft March 2002b).

HACC

The current HACC Data Dictionary Version 1.0, contains definitions underpinning the HACC MDS Version 1.0 which includes information describing the assistance received by HACC clients. [5] While such data provide information about the type and amount of formal assistance the client receives from the HACC agency, it does not give a full picture of the client's dependency-related needs. In 2000 the Australian Government Department of Health and Ageing commissioned a consultancy to develop measures of dependency for people who require HACC services and to define associated data items for inclusion in the HACC minimum data set and data dictionary. The outcomes of this consultancy are documented in the HACC Dependency Report (Eagar et al 2002). This draft report proposes two measurement instruments: the National HACC Functional *Screening* Instrument and the National HACC Functional *Assessment* Instrument. It recommends that, on implementation of the instruments, all nine items of the HACC Functional *Screening* Instrument be included in the HACC MDS. At the time of writing the HACC Functional *Screening* Instrument has been endorsed, while the HACC Functional *Assessment* Instrument remains draft.

Residential aged care

The Resident Classification Scale (RCS), introduced in 1997, is a resource allocation instrument for the residential aged care system. The RCS has eight care categories, with categories 1 to 4 representing the higher care levels and categories 5 to 8 the lower care levels. Although this 'casemix' classification instrument is designed to measure dependency or 'need for care' in the residential care setting, its direct link to funding may in some cases affect measurement outcomes, making comparison of RCS data with other programs unreliable. As a review of the RCS is pending, this dependency report does not contain a detailed comparison of dependency measures in the RCS with measures in the other aged care programs. However, any review of the RCS should consider the need to improve consistency of data collected across the field of aged and community care, and seek to achieve greater consistency of the RCS with other data collections.

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5 The HACC Data Dictionary needs to be viewed in conjunction with the HACC MDS Guidelines Version 1.5, which updates some of the definitions.

2.3 Evolving data collections

Over time, community and residential care programs change their emphasis in terms of policy direction and thus the information that needs to be collected to inform policy. During the past decade, various changes have been made to the measurement and collection of information, including dependency, in the above-mentioned programs. Each time a new data collection or instrument is introduced, or existing ones reviewed, an opportunity exists to achieve a higher level of consistency with other collections in the aged/community care and health care areas and with national standards. The challenge is to find solutions that allow changes to the data collections enabling consistent dependency measurement across programs while at the same time allowing each instrument to measure what it is supposed to measure, in order to meet the imperatives of service delivery.

3 Scope of the project

3.1 Documents for comparison

The following documents are compared in, and are the core documents of, the project:

- *Aged Care Assessment Program (ACAP) Data Dictionary Version 1.0* (supports Minimum Data Set Version 2.0) (AIHW 2002a).
- HACC proposed functional dependency instruments, as described in the *Development of Dependency Data Items – Draft Consolidated Report 2002* (the HACC Dependency Report) (Eagar et al 2002).
- Community Aged Care Package (CACP) Data Dictionary Version 1.0 (AIHW 2002b).

Relevant items from these data collections/instruments have been mapped and compared in detail (see Chapter 5 and Appendix D).

While this project originally aimed to compare dependency items in two aged and community care programs (HACC and ACAP) and the residential aged care program (RCS), the emphasis was shifted during the life of the project. Plans of a likely review of the RCS meant that detailed description of a comparison with the current RCS was not desirable. It is recommended that the review of the RCS consider the need to improve consistency with aged and community care data, and consider the recommendations of this report with regard to improving information on the dependency of aged and community care clients.

The detailed mapping and comparison described in Chapter 5 still includes dependency items in the ACAP and HACC program collections, but also includes items from the CACP program collection. These three programs are all partly or fully funded by the Australian government, and all provide services to frail or disabled (older) people living in the community, with emphasis on enabling their clients to remain living in their own home where possible.

Table 2 in this chapter provides a description of the objectives, target group and source documents for each data collection/instrument considered in this project. It also identifies the data elements or instruments that are relevant to the measurement of dependency (for details on data items, see Table 4), and the corresponding data domains (see Section 3.2 below for an explanation of these terms).

Table 3 provides a description of the objectives and source documents for each national and international standard used in this project. It also identifies the data elements in these standards that are relevant to the measurement of dependency, and the corresponding data domains.

3.2 Terminology

To be able to assess consistency between collections and national/international standards during this project, consistent terminology needed to be defined. Terms such as data item, data element, data domain, data codes and ratings have different meanings in different

contexts, and therefore the appropriate terminology needed to be defined within this context and used consistently.

Data elements, data items and activity groupings

A data element is a unit of data, which may or may not be collected as a part of a data set. A data item, in this report, is synonymous with the term 'activity', and is usually a part (a data code) of a data element. For example, activities such as eating, dressing, transfers and shopping are all classed as a data item. These items can be grouped together to form an 'Activity grouping'. Activity groupings included in the comparability assessment in this report are self-care, mobility and communication: the three groupings that are used by the ABS to measure the level of core activity restriction, a concept used to measure a person's level of need for assistance. These groupings correspond with the groupings used in the ICF at the chapter level. Activity groupings also discussed in this report are Domestic life, Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), Behaviour and Cognition (Section 4.4). Section 4.4 also gives examples of alternative groupings.

Data domain

The term 'data domain' is often referred to in this report. The data domain, referred to as a 'qualifier' in the ICF, describes the coding of each item or, in other words, the range of answers that exist for the question asked about a particular item. For example, the most straightforward question in the context of dependency is whether the help or supervision of another individual is required to undertake an activity. This data domain may be expanded on, for example by asking if the person sometimes or always needs help (e.g. ABS), or if the person needs help with only part of the activity (e.g. HACC Functional Dependency Instruments). In some cases the data domain does not provide an answer to the dependency question, for example in the data domain for 'Managing behaviour' in the HACC Functional *Screening* Instrument (see Table 7 in Appendix D).

'Levels' (see diagrams 1–5 in Appendix B)

In order to assist further understanding of the terminology, in particular the terms 'data item' and 'activity group' and the levels at which these can be visualised, five diagrams are presented in Appendix B. Diagrams 1, 2 and 3 portray two levels, the dependency items included in this report, and some of the activity groups to which those items may be mapped. Diagram 5 includes another, higher, level (core activity restriction). Although there are many ways of combining data items in activity groups, only some groups have been selected for the diagrams. Further examples of activity groups are described in Section 4.4. All diagrams use the terminology from the ICF, which has proven particularly helpful in creating consistency in the identification of each item.

3.3 Data items

Table 4 provides a listing of the data elements/instruments and data items directly related to dependency in the ACAP data collection, the HACC functional dependency instruments and the CACP data collection. Data elements/instruments are identified by bold lettering. Data items contained in the ABS Survey of Disability, Ageing and Carers 1998, the NHDD and the NCSDD that have been used for comparison during this project are listed in Table 5.

Table 2: Program/data collection information

Data collection	Objective(s)	Target group	Document	Data elements / instruments	Data domains
ACAP MDS Version 2	To support policy & program development, planning & performance monitoring and to assist ACATs in improving management & service delivery.	Frail aged people	ACAP Data Dictionary Version 1 (AIHW 2002a)	Activity limitations	Does / does not need help or supervision (in a defined list of activity areas)
HACC Functional Depend-ency Instrument	To assist in evaluating the appropriateness and success of the program and to inform the development of effective strategies for the planning and funding of HACC services.	Frail aged people and people with a disability, and their carers	Development of Dependency Data Items Draft Consolidated Report (Eagar et al 2002)	**1. Proposed functional *screening* instrument:** • Self-care and domestic functioning • Cognition and behavioural functioning **2. Proposed functional *assessment* instrument:** • Self-care functioning • Domestic functioning in activities of daily living • Behavioural functioning • Cognition	Without help With some help Completely unable Yes No The rating varies according to the question The rating varies according to the question Requires monitoring for recurrence and supervision Requires monitoring for recurrence and then supervision on less than a daily basis Requires monitoring but not supervision Does not require monitoring (consumer has not engaged in the behaviour in the past) Specialised scoring system
CACP national census	Data collection to support policy development, program planning, and performance measurement.	Frail older people with complex care needs (equivalent to people assessed by ACATs as eligible for low level residential care)	Community Aged Care Package Data Dictionary, Version 1.0, 2002 (AIHW 2002b)	Core activity limitations	Does / does not need help or supervision

Table 3: International and national standards

Data source	Objective(s)	Document	Data elements / instruments	Coding/rating
ICF 2001	To provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants; To establish a common language for describing health and health-related states in order to improve communication; To permit comparison of data across countries, health care disciplines, services and time; To provide a systematic coding scheme for health information systems.	International Classification of Functioning, Disability and Health (WHO 2001)	Body functions (Chapter 1) Activities and participation (Chapters 3, 4, 5 and 6)	First qualifier: NO problem MILD problem MODERATE problem SEVERE problem COMPLETE problem The use of other qualifiers is encouraged (see Section 1.5).
ABS Disability, Ageing and Carers Survey 1998	To collect information on people with disabilities, older people and those who provide care for people because of their disability.	Disability, Ageing and Carers User Guide 1998 (ABS 1999)	Core activity restriction	In most questions: Always needs help or supervision because of disability Sometimes needs help or supervision because of disability Does not need help or supervision but has some difficulty Has no difficulty In some questions a different data domain is used.
NCSDD Version 2	To communicate a coherent set of data standards that improve the availability and maintenance of high-quality data about the needs of the community, the services provided, and the outcome of these services, including any unmet demand.	National Community Services Data Dictionary, Version 2 (AIHW 2000a)	Activity areas (qualified by 'Assistance with activity' and 'Activity—level of difficulty')	Two data domains[6] Data domain related to dependency: No assistance used Non-personal assistance Personal assistance Both non-personal and personal assistance
NHDD Version 12	To establish a core set of uniform definitions relating to the full range of health services and a range of population parameters (including health status and determinants).	National Health Data Dictionary Version 12, (AIHW 2001)	Dependency in activities of daily living	Coding varies depending on the activity. (in a defined list of activity areas)

6 The area in which an individual experiences an activity limitation is indicated in the data element 'Activity areas'. The extent of the activity limitation is indicated in 'Activity—level of difficulty'. 'Assistance with activity' indicates the type of assistance the individual currently has in a given area of activity.

Table 4: Dependency data elements/instruments and data items: ACAP and CACP data collections, HACC Functional Dependency Instruments

ACAP	CACP	HACC Dependency Instrument: Functional Screening Instrument	HACC Dependency Instrument: Functional Assessment Instrument
Activity limitations Self-care Movement activities Moving around places at or away from home Communication Health care tasks Transport Activities involved in social and community participation Domestic assistance Meals Home maintenance Other	**Core activity limitations** Eating Showering/bathing Dressing Toileting Managing incontinence Maintaining or changing body position Carrying, moving and manipulating objects related to the tasks of daily living Getting in or out of a bed or a chair Walking and related activities (includes moving around the home or away from home, but excludes needing transport assistance) Using public transport (e.g. buses, trains) Understanding others or making oneself understood by others (excludes the independent use of aids and equipment)	**Self-care and domestic functioning** Housework Transport Shopping Medication Finances Walking Bathing/showering **Cognition** Memory/confusion **Behavioural functioning** Behavioural problems	**I Self-care functioning** Bowels Bladder Grooming Toilet use Feeding Transfer Mobility Dressing Stairs Bathing (or showering) **II Domestic functioning in activities of daily living** Telephone Shopping Food preparation Housekeeping Laundry (excludes ironing) Mode of transportation Responsibility for own medications Ability to handle finances **III Behavioural functioning** Problem wandering or intrusive behaviour Verbally disruptive or noisy Physically aggressive Emotional dependence Danger to self or others **IV Cognition** Orientation Registration Attention and calculation Recall Language

Table 5: Dependency data items: ABS Survey of Disability, Ageing and Carers 1998, NHDD and NCSDD

ABS Survey of Disability, Ageing and Carers 1998	NHDD Version 12	NCSDD Version 2
Communication Understanding family/friends Being understood by family/friends Understanding strangers Being understood by strangers **Mobility** Getting into/out of bed/chair Moving about usual place of residence Moving about a place away from usual residence Ability to use public transport Bending to pick something up off the floor **Self-care** Showering/bathing Dressing Eating Toileting Managing incontinence **Health care** **Paperwork** **Transport** **Housework** **Property maintenance** **Meal preparation** **Guidance**	**Dependency in activities of daily living** Mobility Toileting Transferring Bathing Dressing Eating Bed mobility Bladder continence Bowel continence Extra surveillance Technical care	**Activity areas** Activities of learning and applying knowledge Communication activities Movement activities Activities of moving around Self-care activities Domestic activities **Activity—level of difficulty** **Assistance with activity**

4 Comparing dependency

4.1 Comparison: what and how

As discussed in Chapter 1, each aged and community care program collects dependency information specific to its own service delivery needs, and national data are a by-product of this process. Improving consistency between national dependency data may have repercussions for the information collected in each program. This begs the question: why, what and how should dependency information be compared? Section 1.2 of this report lists a number of reasons why the capacity to compare dependency data may be of importance. This section offers further thoughts on what data comparisons may be of value for policy development, program planning and performance monitoring, and how these could be carried out in order to be most useful.

To further clarify, by visual means, the types of comparisons that could be done with consistent data, some 'dummy' graphs are presented below. Note that the data used in these graphs have been invented, and the programs are fictional.

Across-program comparisons

Across programs, comparison may be useful at all the levels presented in diagrams 1–5, in Appendix B.

At the data item level, need for assistance with specific activities may be compared, e.g. need for assistance with bathing, taking medications, or moving around in different locations, which may assist in comparing service needs. The figure below (Figure 3) provides an example, using dummy data and fictional programs and shows the percentage of clients who need assistance with taking medications in each program.

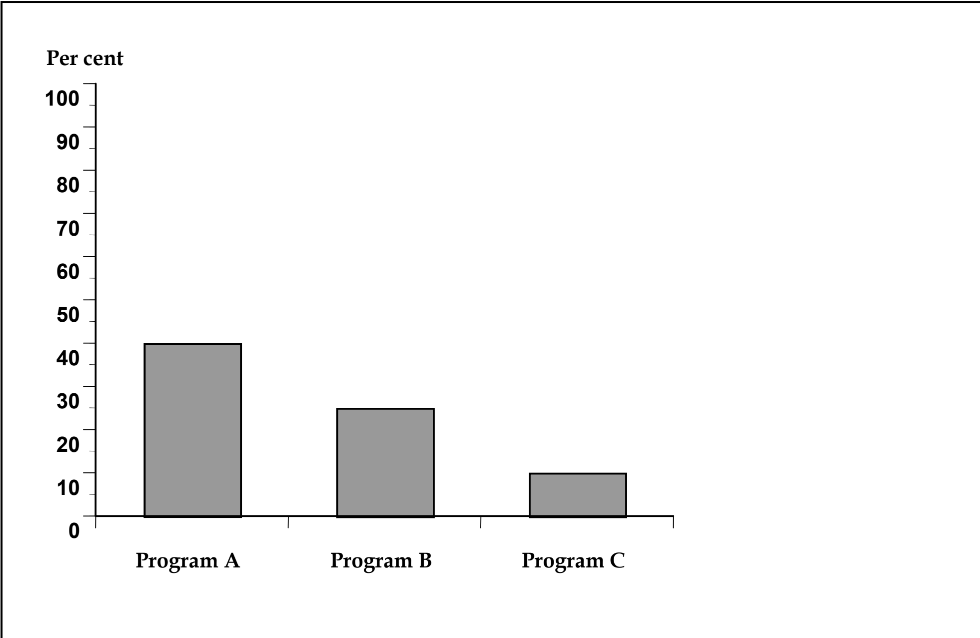

Figure 3: Need for assistance with taking medications (dummy data)

The data item level also allows for comparing the extent of dependency in clients, i.e. the need for assistance with only one activity, with several or with all. The example in Figure 4 shows the proportion of clients in each program by extent of dependency. As well as allowing such information to be compared across programs, consistency would also allow the merging of data across programs to assist in building a profile of all aged and community care clients.

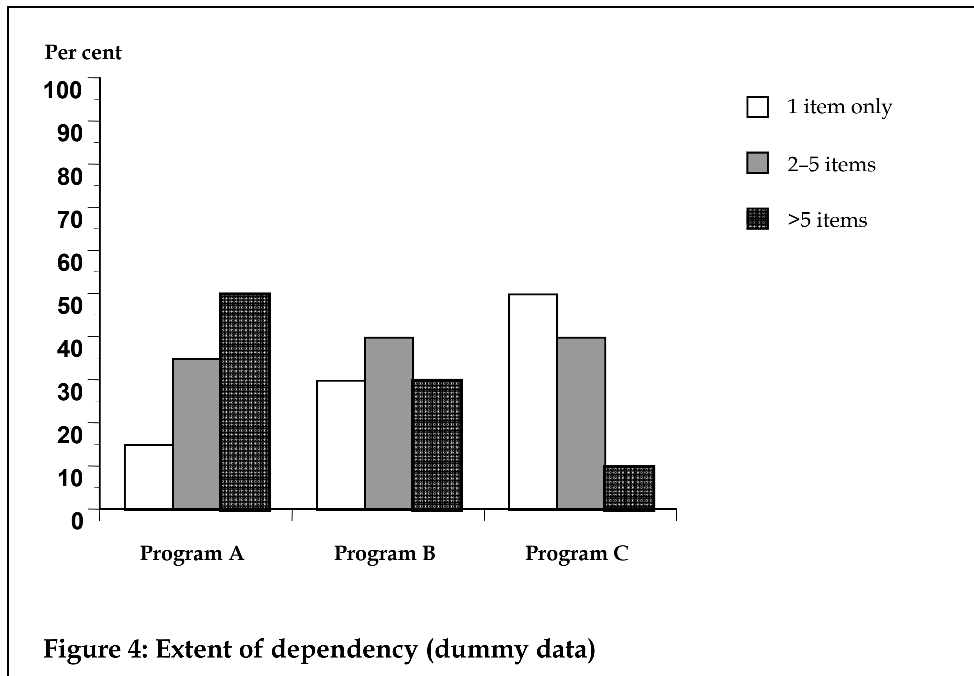

Figure 4: Extent of dependency (dummy data)

The next level up, which contains groupings such as self-care or domestic life, also allows for comparing the extent of dependency, but at an activity group level. For example, some clients need assistance with domestic tasks only, others need assistance with both domestic tasks and with mobility. Section 4.4 in this chapter provides some examples of different activity groupings that can be formed using the basic 'building blocks' (data items). Figures 5 and 6 provide examples of this type of comparison by showing the proportion of clients in each program by activity group dependency.

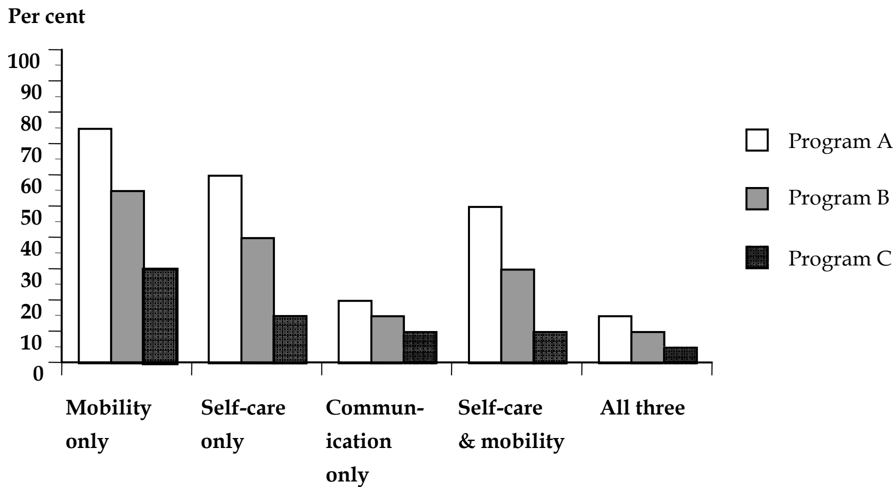

Figure 5: Need for assistance with self-care etc. (dummy data)

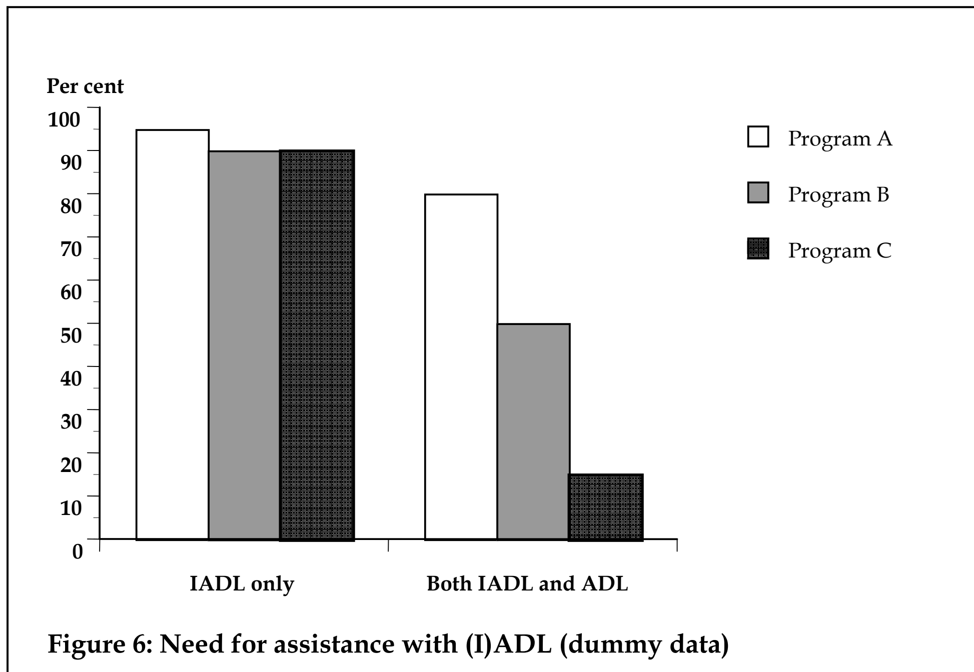

Figure 6: Need for assistance with (I)ADL (dummy data)

Although 'core activity restriction' (the highest level in diagram 4, Appendix B) is originally a concept introduced by the ABS in relation to population data, it may also be used in across-program comparisons. For example, one could compare the proportion of clients in each program with a severe or profound core activity restriction. Some programs may have higher proportions of clients with a core activity restriction than others. This information could also assist in building a profile of all aged and community care clients.

Population comparisons

In the context of national program performance monitoring, in particular in the performance areas of access and equity, comparison of program dependency data with population data has the potential to provide useful information about access to services.

For example, a comparison of the proportion of older (or younger) clients with a severe or profound core activity restriction (the highest level in diagram 5) with the proportion in the

wider community will provide an indication of how need is met by the programs. The detailed mapping in this report includes a consistency assessment with the ABS data items, as lack of consistency at the lower levels has implications for comparison at the core activity restriction level.

Dependency data and environmental factors/health condition

Dependency information may also be combined with other relevant related data such as environmental factors or information on health conditions. For example, analyses could be done on the proportion of clients with a core activity restriction together with information on whether those clients live alone or have a carer, or whether they have been diagnosed with dementia (Figure 7 provides an example of such a comparison).

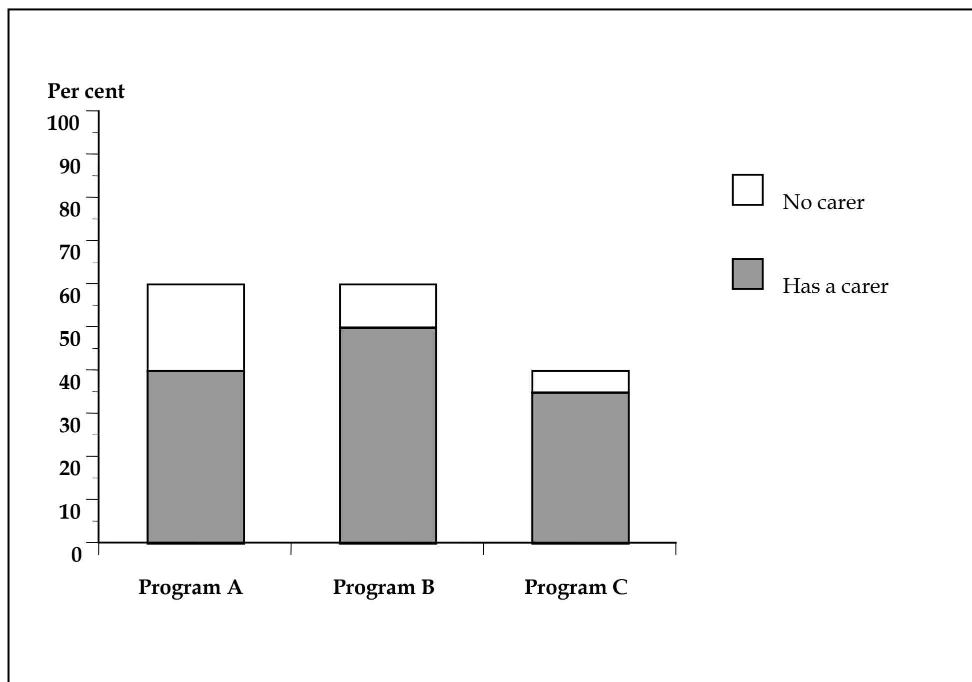

Figure 7: Core activity restriction and presence of a carer (dummy data)

Trends

For every type of comparison mentioned above, changes over time may be compared between programs. There may be increases/decreases in dependency in self-care over a period of time, in the need for assistance with domestic tasks, or in a specific activity such as managing incontinence, walking or housework. Examination of trends in the proportion of clients with a core activity restriction may also be of interest.

4.2 Methodology

The first step in the process of comparing dependency in activities was to identify the items across the aged and community care programs that were relevant to dependency. The ICF domains of Activity and Participation were used to broadly scope the items that could be considered direct measurements of dependency. Items were included in the comparison work if they could be classified using the ICF structure and were measured across more than one program (or one aged care program and the ABS survey). Additionally, items not in scope of the ICF were included in the comparison where they were part of one of the 'accepted' activity groupings as used in the field of aged care (e.g. self-care, instrumental

activities of daily living (IADL), etc.) (see Section 4.4) and they were measured across more than one program. An ICF code was then allocated to each of the items on the resulting list where such a code existed (see Table 6, Appendix A). The items, or relevant activity groupings, were then identified in the national standards to enable comparisons (see Table 3). All dependency data items were ordered according to the groupings self-care, mobility, communication, domestic life, cognition and behaviour.

The data domain for each item was ascertained and, following on from this, it was determined whether the data domain described need for assistance and, if so, whether it could be mapped to the basic categorisation of need/no need for personal assistance.

Mapping of data items to a simple dichotomy of either need/no need for personal assistance was undertaken to enable comparison of the data items (for detail, see Appendix D). The majority of data items have a unique data domain, and cannot be directly compared. In general, the data domain reflects the information requirements for service delivery in the program. For example, the data domain of items in the HACC Functional *Assessment* Instrument reflects the type of service response. It is important that each collection retain its unique data domains; however, it is essential that a unique data domain can be mapped to a common domain to enable comparison of the data items. Defining the need for personal assistance as the common domain was determined to be the most relevant basis for comparison.

In comparing items between programs and with (inter)national standards (see Section 5.1: Item comparisons), the decision whether consistency exists between items was based on two considerations—firstly, whether each item was mappable to the categorisations need/no need for personal assistance, and, secondly, whether the definition/meaning of the items was consistent.

Following a comparison of individual items, an assessment was done to determine whether consistency in the data collections existed at an activity group level. In order to carry out a comparison of data collections using possible activity groupings, each item was mapped to a relevant activity grouping, for example, self-care. Comparisons of consistency were then made across the programs at the activity group level.

4.3 Aids and equipment

Dependency as defined in this report is the need for assistance from another person to carry out an activity. This definition is consistent with that used in the NHDD and the ABS. Using this definition, a person is regarded as being independent where they use aids and equipment only to assist in carrying out an activity, as there is no need for personal assistance.

The distinction made by the NCSDD, NHDD and the ABS between the need for assistance from another person and the sole use of aids and equipment to carry out an activity reflects the different and more significant impact that the need for personal assistance has on the person, as well as the implications for care and service delivery.

In the comparison of data items used to measure dependency, mapping of each data item to a simple dichotomy of need/no need for personal assistance has been employed to enable comparisons to be made. The use of aids and equipment has required particular consideration in this process. The need for personal assistance and the use of aids and equipment are not always consistently or clearly defined for a data item. Three issues in

particular impact on the ability to undertake a simple mapping and the usefulness of that mapping.

The first issue is the lack of clarity in some collections in the definition of data items with regard to the inclusion of aids and equipment. Some data items do not specifically state whether aids and equipment are included in consideration of the data item, or how they should be coded.

The second issue is the lack of consistency in the data domain. The independent use of aids and equipment is not always given a code to enable it to be identified separately from the need for personal assistance. In addition, the use of aids and equipment may not be stated as independent use, and it is therefore not known whether personal assistance is also required.

The third issue is the inconsistency in the purpose of the data item. The HACC Functional Instruments, the ABS Survey, the NHDD and NCSDD record the person's need for personal assistance in the present, regardless of whether the person would need that assistance if they were supplied with aids or equipment, while the ACAP and CACP programs record the person's need for personal assistance if they were provided with the necessary equipment. Another point to note is that this approach assumes the assessor is suitably qualified to make that judgment. This issue, however, is not further discussed as it is beyond the scope of this report.

In this report, the use of aids and equipment is mapped to independence (with regard to the need for personal assistance) only where the use, or potential use, of aids and equipment is clearly identified.

4.4 Activity groups

When making comparisons of dependency measures, and consequently to be able to make comparisons of dependency levels of clients in aged and community care programs, using the individual items pertaining to the measurement of dependency as the basic unit of comparison permits the construction of a number of summary measures of dependency. Individual items can be grouped into any combination to suit specific purposes such as analysis or service delivery support. The most commonly used activity groups in the field of aged and community care can be viewed as alternate groupings of the individual items. No one particular combination of activities will comprehensively measure the need for assistance of the population under consideration.

The activity groups used most frequently to measure need for assistance are 'Core activities', which consists of the subgroups self-care, mobility and communication, and the 'Activities of daily living' (ADLs) and 'Instrumental activities of daily living' (IADLs).

Core activities

Core activities are defined by the ABS in its Survey of Disability, Ageing and Carers and are the activities of self care, mobility and communication. A person is defined as having either a profound, severe, moderate or mild core activity restriction depending on the level of assistance required and/or the level of difficulty with the activities of self care, mobility and communication. Someone with a severe or profound core activity restriction is defined as sometimes or always needing assistance from another person with the activities of self care, mobility or communication. The ABS survey thus provides population data on the extent and level of disability and need for assistance in the Australian community. Applying the

concept of severe or profound core activity restriction to the programs in aged care allows comparison of aged care clients with the wider population, and provides a valuable tool to measure accessibility. It also provides a measure with which to compare clients across the aged care programs. Performance indicators developed for the ACAP program, and the draft performance indicators for the CACP program and the residential aged care program use the concept of profound or severe core activity restriction to measure program performance in the areas of equity, effectiveness and access. Comparisons of dependency measures using the group 'Core activities' and its component groups self-care, mobility and communication have been included in this report. The items included in these groups are:

- self-care—eating, washing oneself, dressing, toileting, managing incontinence;
- mobility—changing and maintaining body position, moving around in different locations, using transport, lifting and carrying objects;
- communication—defined at the group level, no component items or activities are included in any of the three aged and community care programs.

ADL and IADL

ADLs and IADLs are not uniformly defined. There is a range of published instruments to measure need for assistance with ADLs and with IADLs. Instruments have been designed for different purposes and therefore differ in their emphasis and the activities which are included (refer Stage 1 HACC Dependency Report). However, it is possible to compile a group of items that are consistently included in many of these instruments.

The ADL items identified for this project as measured by more than one aged or community care program (or one aged care program and the ABS Survey) and included in at least four published and commonly used ADL instruments are: managing incontinence, eating, washing oneself, dressing, toileting, changing and maintaining body position, and mobility. For the IADL group they are: shopping, preparing meals, housework/laundry, money management/paperwork, using transport and taking medications. The ADL and IADL groups have been used to guide the selection of data items for comparison.

The use of the ADL and IADL groups in the context of the aged and community care programs can provide a measure of the need for assistance with activities that are commonly considered to be of importance, and could be used to compare clients across aged care programs.

An alternative method of grouping ADL and IADL items has been suggested by Thomas et al (1998). The authors propose the use of three groups: Basic self-care, Intermediate self-care and Complex self-management, where the first group includes ADL items only, the third group includes IADL items only, but the intermediate group includes a combination of ADL and IADL items.

Comparisons of dependency measures at the activity group level for the ADL and IADL groups have not been included in this report.

Other activity groups

Alternatively, individual items can be grouped to form any combination of activities that may be of interest. An example of applying an alternative grouping of activities is provided in *Australia's Welfare 1997* (AIHW 1997a). Using the items collected in the ABS Survey of Disability, Ageing and Carers 1993, four activity groups were constructed, and estimates

made of the population with a disability who required assistance with each of these four groups of activities.

- Group 1 comprised activities of showering/bathing, dressing, eating/feeding, toileting, bladder/bowel control, moving about the house, transfers between bed and chair, communicating with family/friends.
- Group 2 comprised activities of moving around places away from home, communicating with people one does not know, home help, meal preparation, taking medication/dressing wounds, financial management/writing letters, shopping.
- Group 3 comprised activities of home maintenance, public transport, driving, footcare.
- Group 4 comprised all persons who do not need assistance with the activities included in groups 1–3.

The population with a disability was further defined according to the profound, severe, moderate and mild restriction classification as defined in the ABS Survey. From this analysis, it was noted that a substantial proportion of people who are classified as having a mild restriction (which by definition means they do not need help and do not have difficulty with any of the core activity tasks) do need assistance with Group 2 activities.

This example demonstrates the usefulness of individual data items in making comparisons of dependency. Using individual data items allows activities to be grouped depending on the purpose, and the example further illustrates that any measure of dependency is not comprehensive.

4.5 Hierarchy of activities: HACC

The proposed HACC Functional Dependency Instruments consist of two separate instruments: the HACC Functional *Screening* Instrument designed to screen all HACC clients and the HACC Functional *Assessment* Instrument to more fully assess a subset of HACC clients. The Functional Screening Instrument aims to act as a 'filtering system'. It has been designed to be administered in a short time and by service providers with minimal training in the use of the instrument. The Functional Screening Instrument includes a subset of items from the ADL and IADL scales, and is based on the premise that 'ADL and IADL activities form a hierarchical order in which some activities are generally lost before others' (Eagar et al 2002:21; see also Dunlop et al 1997). This means that, if a person does not need assistance with an activity that is usually lost before others, then it is unlikely that this person needs assistance with any other tasks. Consequently, the limited number of questions chosen for the screening instrument have been based on the hierarchical order as suggested in a selection of studies (Eagar et al 2002:21).

The authors of the HACC Dependency Report acknowledge that some care needs to be exercised in applying the theory on hierarchy. It is unlikely that all clients will fit into the hierarchy model and, in fact, some variation was noted in the relevant studies. Also, the study population consisted of mainly older people, and this means that it is unclear how valid the hierarchy theory and therefore the screening instrument will be for young people with disabilities. It is also unclear how the phrasing of the question for each item might affect how dependency is captured (Eagar et al 2002:21; Hoeymans et al 1996).

The HACC Functional Screening Instrument consists of nine items: housework, using transport, shopping, taking medication, handling money, walking, bathing/showering, cognition/memory, behaviour. While the proposed HACC Functional Screening Instrument

may be useful for categorising clients via a screening process, it will not provide comprehensive data on the self-care, mobility or domestic needs of all HACC clients. The HACC Dependency Report recommends that the nine items be included in the HACC Minimum Data Set (MDS). Although this addition to the HACC MDS will enhance the availability of national data on HACC clients, it will create inconsistencies with other aged and community care collections and national standards.

If the 'hierarchy theory'were accepted, one could argue that it would allow for comparison of data, albeit a fairly rough comparison. This is best demonstrated through an example. If, according to the outcome of the HACC screening tool, a client does not need assistance with bathing/showering, it is assumed unlikely that the person needs assistance with any of the other self-care activities. It could thus be argued that data on the needs of all HACC clients in relation to the activity grouping self-care can be compared with those of clients in the ACAP or CACP programs. A client who 'passes' the screening test on bathing/showering would presumably not need assistance from another person with self-care and is therefore independent in self-care. On the other hand, a client who needs help with bathing/showering is automatically classified as dependent in the activity grouping of self-care.

In order to align with the ICF and national standards, and to be able to compare national HACC data with other aged and community care national data, the HACC NMDS would need to include, at a minimum, a data element that supports the reporting of self-care, mobility and communication. If the hierarchy theory were accepted, all activities of self-care and all activities of mobility are implied as being included in the HACC Functional Screening Instrument through a limited number of questions on self-care and on mobility. However, it is doubtful that the hierarchy theory can be applied to data collection in this way. Moreover, no question on communication is currently included in the HACC Functional Screening Instrument.

5 Mapping dependency data items

5.1 Item comparisons

As described under Methodology (Section 4.2), a comparison was made of all data items relevant to measuring dependency. Appendix D consists of the table of data items which lists their data domains and includes a mapping of the data domains to the need for personal assistance. The items are considered according to the activity groupings self care, mobility, communication, domestic life, behaviour and cognition, and the results of the comparison are discussed in detail below.

5.1.1 Self-care and related items

Incontinence (ICF codes b6202 and b5253)

Definition and classification

Urinary and defecation functions, including (in)continence, are classified in the Body functions domain of the ICF (Chapter 5 and 6). 'Managing incontinence' is included in some of the data collections and standards, including the ACAP, CACP, ABS and the NCSDD. Incontinence as a condition, rather than the need for assistance, is included in the NHDD and the HACC Functional Assessment Instrument. As a condition it is also included in the ACAP collection in the data element 'Health condition', using the ICD-10-AM classification.

Incontinence refers to both incontinence of the bowels and incontinence of the bladder. Bladder and bowel incontinence are separately identified in both the HACC Functional *Assessment* Instrument and in the NHDD. In all other collections, the items 'incontinence' or 'managing incontinence' do not distinguish between bladder and bowel incontinence.

Personal assistance

In CACP and ABS, the item refers to managing incontinence and it is possible to determine whether the assistance or supervision of another person is required to manage incontinence. In ACAP and the NCSDD, managing incontinence is included in the category of self-care activities but they do not separately identify the need for personal assistance with managing incontinence.

In the remaining data collections and standard where the item 'incontinence' is identified—the HACC Functional *Assessment* Instrument and the NHDD—the item is a description of the person's condition and the frequency of the condition, but does not include identification of need for personal assistance with managing incontinence. However, data on the presence of the health condition 'incontinence', in conjunction with the item 'toileting' (see related text in this section under the heading 'Toileting'), provide the information necessary to determine whether a person requires personal assistance with managing incontinence.

Comparison

Incontinence—Item level:

Dependency with regard to incontinence can be compared at the item level across the HACC Functional *Assessment* Instrument, CACP, ABS and the NHDD, using the simple categorisation of need/no need for personal assistance. In the case of the HACC Functional *Assessment* Instrument and the NHDD, this item-level comparison requires the use of two items, the item 'incontinence' (as a health condition) and the item 'toileting' (need for assistance). The ACAP and the NCSDD include the item 'self-care activities', which incorporates incontinence, but they do not separately identify the need for personal assistance with incontinence. The HACC Functional *Screening* Instrument does not include a question on incontinence, and can therefore not be compared at this level with the other collections.

Eating (ICF code d550)

Definition and classification

Eating is classified under Activities and Participation in the ICF, and it is defined at the four digit level of the classification. Eating is included in each of the data collections, though not in the HACC Functional *Screening* Instrument, and is defined as an activity. It is not clear in the data collections whether drinking is included in the activity of eating. In the ICF, the activity of drinking is separately defined and classified at the four digit level.

Personal assistance

The HACC Functional *Assessment* Instrument, CACP, ABS and NHDD data items for eating all identify a person's need for personal assistance with eating. While the data domain of each is unique, it is possible to map each data domain to a simple categorisation of need/no need for personal assistance, regardless of the degree of need.

The ACAP and the NCSDD include the item 'self-care activities', which incorporates eating, but they do not separately identify the need for personal assistance with eating. The HACC Functional *Screening* Instrument does not include a question on eating.

Comparison

Eating—Item level:

Dependency with regard to the activity of eating can be compared across the HACC Functional *Assessment* Instrument, the CACP, ABS and NHDD at the item level, using the simple categorisation of need/no need for personal assistance.

The ACAP and NCSDD do not separately identify eating from the group of self-care activities and can therefore not be compared in terms of the need for assistance with eating. The HACC Functional *Screening* Instrument can also not be compared at this level as it does not separately identify eating.

Washing oneself (ICF code d510)

Definition and classification

Washing oneself, which includes bathing and showering, is classified under Activities and Participation in the ICF, and it is defined at the four digit level of the classification. Washing oneself is included in each of the data collections, including the HACC Functional *Screening* Instrument, and is defined as an activity.

Personal assistance

The data domains of the HACC Functional *Assessment* and *Screening* Instruments, CACP, ABS and NHDD can all be mapped to need/no need for personal assistance with bathing/showering. The ACAP and the NCSDD include the item 'self-care activities', which incorporates bathing/showering, but they do not separately identify the need for personal assistance with bathing/showering.

Comparison

Bathing/showering—Item level:

As a result, the HACC Functional *Screening* Instrument, the HACC Functional *Assessment* Instrument, the CACP, ABS and NHDD can all be compared at the item level in terms of the person's need for assistance with bathing/showering. The ACAP and NCSDD do not separately identify bathing/showering from the group of self-care activities and can therefore not be compared at the item level.

Dressing (ICF code d540)

Definition and classification

Dressing is classified under Activities and Participation in the ICF, and it is defined at the four digit level of the classification. Dressing is included in each of the data collections, though not in the HACC Functional *Screening* Instrument, and is defined as an activity.

Personal assistance

The data domains of the HACC Functional *Assessment* Instrument, the CACP, ABS and NHDD data collections can be mapped to need/no need for personal assistance with dressing. The ACAP and the NCSDD include the item 'self-care activities', which incorporates dressing, but they do not separately identify the need for personal assistance with dressing. The HACC Functional *Screening* Instrument does not include a question on dressing.

Comparison

Dressing—Item level:

Dependency with regard to the activity of dressing can be compared across the HACC Functional *Assessment* Instrument, the CACP, ABS and NHDD at the item level, using the simple categorisation of need/no need for personal assistance.

The ACAP and NCSDD do not separately identify dressing from the group of self-care activities and can therefore not be compared in terms of the need for assistance with dressing. The HACC Functional *Screening* Instrument can also not be compared at this level as it does not identify dressing.

Toileting (ICF code d530)

Definition and classification

Toileting is classified under Activities and Participation in the ICF, and it is defined at the four digit level of the classification. Toileting is included in each of the data collections and national standards, except in the HACC Functional *Screening* Instrument, and is defined as an activity. The ICF includes the lower level codes 'Regulating urination' and 'Regulating defecation'.

Personal assistance

The data domains of the HACC Functional *Assessment* Instrument, the CACP, ABS and NHDD data collections can be mapped to need/no need for personal assistance with toileting. The ACAP and the NCSDD include the item 'self-care activities', which incorporates toileting, but they do not separately identify the need for personal assistance with toileting. The HACC Functional *Screening* Instrument does not include a question on toileting. In conjunction with data on the presence of the health condition 'incontinence', the item 'toileting' also provides the information necessary to determine whether a person requires personal assistance with managing incontinence.

Comparison

Toileting—Item level:

Dependency with regard to the activity of toileting can be compared across the HACC Functional *Assessment* Instrument, the CACP, ABS and NHDD at the item level, using the simple categorisation of need/no need for personal assistance.

The ACAP and NCSDD do not separately identify toileting from the group of self care activities and can therefore not be compared in terms of the need for assistance with toileting. The HACC Functional *Screening* Instrument can also not be compared at this level as it does not include a question on toileting.

Maintaining one's health (ICF code d5702)

Definition and classification

Maintaining one's health is classified under Activities and Participation in the ICF, and it is defined at the five digit level of the classification. Maintaining one's health is included in the ACAP data collection, the NCSDD, the NHDD and the ABS survey, and is defined as an activity.

Personal assistance

Terminology to describe the concept of maintaining one's health differs across the data collections. Maintaining one's health is a broad grouping of activities that includes, but is not limited to, taking medication, administering injections, dressing wounds, foot care, using medical machinery, manipulating muscles or limbs. Three collections—ACAP, ABS, NHDD—separately record the need for assistance with maintaining one's health.

Comparison

Maintaining one's health—Item level:

As discussed above, the HACC Functional *Screening* Instrument and the HACC Functional *Assessment* Instrument collect information on the need for assistance with taking medications, which can then be mapped to the level of health care tasks. However, the mapping applies to the activity of taking medications only. All other health care tasks are not identified in these two collections. The CACP collection does not collect information on the need for assistance with health care tasks. The NCSDD groups all health care tasks under self-care activities and health care tasks cannot be separately identified. Therefore, comparisons of the need for assistance with health care tasks can only be made between the ACAP, ABS, and NHDD.

Taking medications (no separate ICF code)

Definition and classification

Taking medications is included under code d5702, Maintaining one's health, under Activities and Participation in the ICF, but it is not defined separately in the ICF classification. Taking medications is included in each of the data collections, except the CACP data collection, and is defined as an activity.

Personal assistance

The activity of taking medications is only separately defined in the HACC Functional *Assessment* and HACC Functional *Screening* Instruments. The data domain of both these collections can be mapped to need/no need for personal assistance with taking medications.

In the ACAP and ABS collections and in the NHDD and NCSDD, taking medications is incorporated in items such as 'health care tasks' and 'looking after one's health', therefore it is not possible to separately identify the need for assistance with taking medications. The CACP Program does not collect information on the need for assistance with taking medications.

Comparison

Taking medications—Item level:

Only the HACC Functional *Screening* and HACC Functional *Assessment* Instruments are comparable at the data item level. All other collections do not separately identify the need for assistance with taking medications from the group of health care tasks and can therefore not be compared in terms of the need for assistance with taking medications.

5.1.2 Mobility and related items

Changing and maintaining body position (ICF code d410–d420)

Definition and classification

Changing and maintaining body position is classified under Activities and Participation in the ICF, and consists of a range of codes. The following codes are included: d410, Changing basic body position; d415, Maintaining a body position; and d420, Transferring oneself. The three items are defined as activities in the ICF. Changing and maintaining body position is included in the ACAP and CACP data collections, and in the NCSDD. The HACC Functional *Assessment* Instrument and the ABS only include the third of these three items, i.e. transfers. The NHDD separately identifies bed mobility and transfers. Bed mobility has a very limited definition compared with the broader 'changing basic body position'. The HACC Functional *Screening* Instrument does not include any of these three items.

Personal assistance

The activity of changing and maintaining body position is only specifically identified in the CACP collection. The data domain of this collection can be mapped to need/no need for personal assistance with changing and maintaining body position. In the ACAP and NCSDD, changing and maintaining body position is included in 'mobility' or 'movement activities', but is not separately identified.

The HACC Functional *Assessment* Instrument, the ABS and the NHDD can be mapped to need/no need for personal assistance with transferring oneself, but not with the broader 'changing and maintaining body position'.

Comparison

Changing and maintaining body position—Item level:

As mentioned above, dependency with changing and maintaining body position is only specifically identified in the CACP collection, and can therefore not be compared across the data collections.

Dependency with regard to transferring can be compared across the HACC Functional *Assessment* Instrument, the CACP, ABS and NHDD at the item level, using the simple categorisation of need/no need for personal assistance.

The ACAP and NCSDD do not separately identify transfers from the group of movement activities and can therefore not be compared in terms of the need for assistance with transfers. The HACC Functional *Screening* Instrument can also not be compared at this level as it does not include a question on transfers.

Walking (ICF code d450)

The need for assistance with walking is only separately identified in the HACC Functional *Screening* Instrument. All other data collections and national standards include walking in a broader item, e.g. 'walking and related activities', 'activities of moving around'. This implies that the programs place more importance on the ability to move around independently than on the, narrowly defined, ability to walk. As a result, this report does not include a comparison of the activity 'walking'. Instead, it focuses on the broader item 'Moving around in different locations'.

Moving around in different locations (ICF code d460–d469)

Definition and classification

Moving around in different locations is classified under Activities and Participation in the ICF, and it is defined at the four digit level of the classification. Moving around in different locations is included in each of the data collections, except the HACC Functional *Screening* Instrument, and is defined as an activity. The HACC Functional *Screening* Instrument only identifies the activity 'walking'. It should be noted that, although most of the data collections and national standards include moving around in different locations, these items are not uniformly defined. Some data collections include one or several of the following: the use of aids and equipment; the activity of climbing stairs; and moving around indoors only.

The ABS collection separately identifies moving about the place of residence and away from the place of residence. The HACC Functional *Assessment* Instrument identifies only mobility indoors, that is, about the place of residence. In all other collections, the item moving around in different locations does not distinguish between mobility at home or outside the home.

Personal assistance

The data domains of the HACC Functional *Assessment* Instrument, the ACAP, the CACP, ABS and NHDD data collections can all be mapped to need/no need for personal assistance with moving around in different locations. The NCSDD includes the item 'activities of moving around' which incorporates using transportation, but does not separately identify the need for personal assistance with moving around in different locations.

The HACC Functional *Assessment* Instrument, the ACAP, CACP and NHDD all take into consideration the independent use of aids and equipment including a wheelchair, when assessing dependency in moving around such that, if the person can independently use a wheelchair to assist them in moving around, they are then recorded as being independent of personal assistance.

The HACC Functional *Screening* instrument, however, collects information about walking only, and does not include related activities or the use of a wheelchair. It also makes a distinction between types of aids, and records a person who uses aids such as a walker or crutches in the same category as someone who requires personal assistance, thus making the need for personal assistance indistinguishable.

Comparison

Moving around in different locations—Item level:

Dependency with regard to moving around in different locations can be compared across the ACAP, the CACP, ABS and NHDD at the item level, using the simple categorisation of need/no need for personal assistance.

The HACC Functional *Screening* Instrument is not comparable as it does not distinguish dependence on personal assistance from dependence on aids and equipment and the HACC Functional *Assessment* Instrument is also not comparable because it includes only moving around indoors.

The NCSDD does not separately identify moving around in different locations from the group of activities of moving around and can therefore not be compared in terms of the need for assistance with moving around in different locations.

Moving around using transportation (ICF code d470–d475)

Definition and classification

Moving around using transportation is classified under Activities and Participation in the ICF, and it is classified through a range of codes. The following two codes are included: d470, Using transportation; and d475, Driving. Moving around using transportation is included in each of the data collections, except the NHDD, and is defined as an activity. Driving is included in the ICF, the ACAP data collection and the HACC Functional *Assessment* Instrument, but not in the other data collections.

Personal assistance

The data domains of the HACC Functional *Assessment* and *Screening* Instruments, the ACAP, the CACP and ABS data collections can all be mapped to need/no need for personal assistance with using transport. The NCSDD includes the item 'activities of moving around', which incorporates using transport, but does not separately identify the need for personal assistance with using transport. The NHDD does not include an item on using transport.

Comparison

Using transport—Item level:

Dependency with regard to using transport can be compared across the HACC Functional *Assessment* and *Screening* Instruments and the ACAP data collection at the item level, using the simple categorisation of need/no need for personal assistance.

However, the CACP and ABS data collections are not comparable, as driving is not included, while it is included in both HACC Functional Instruments and in the ACAP collection.

The NCSDD does not separately identify using transport from the group of activities of moving around and can therefore not be compared in terms of the need for assistance with using transport.

Lifting and carrying objects (ICF code d430)

Definition and classification

Lifting and carrying objects is classified under Activities and Participation in the ICF, and it is defined at the four digit level of the classification. Lifting and carrying objects is included in the ACAP and CACP data collections, and in the NCSDD, and is defined as an activity.

Personal assistance

The activity of lifting and carrying objects is only specifically identified in the CACP collection. The data domain of this collection can be mapped to need/no need for personal assistance with regard to lifting and carrying objects. In the ACAP and NCSDD, lifting and carrying objects is included in 'mobility' or 'movement activities', but is not separately identified.

The HACC Functional Instruments, the ABS and the NHDD do not include the need for assistance with lifting and carrying objects, either separately or incorporated in another item.

Comparison

Lifting and carrying objects—Item level:

As mentioned above, dependency with lifting and carrying objects is only specifically identified in the CACP collection, and can therefore not be compared across the data collections.

5.1.3 Communication

Communication (ICF Chapter 3, Activities and Participation component)

Definition and classification

Communication is classified under Activities and Participation in the ICF, and it is defined at the chapter level of the classification. This chapter of the ICF distinguishes between receiving and producing messages, but does not distinguish between communicating with family/friends and strangers. The definition of the ABS core activity 'communication' includes the need for assistance with understanding family/friends, being understood by family/friends, understanding strangers and being understood by strangers. The ACAP and CACP data collections and the NCSDD do include communication, but they do not include further detail.

Communication is not included in the HACC Functional Dependency Instruments or the NHDD.

Personal assistance

The data domains of the ACAP, CACP, ABS and NCSDD can be mapped to need/no need for personal assistance with communication. The HACC Functional *Screening* and *Assessment* Instruments do not include a question on communication. The NHDD also does not identify the need for assistance with communication.

> ***Comparison***
>
> **Communication—Item level:**
>
> Dependency with regard to communication can be compared across ACAP, CACP, ABS and NCSDD, using the simple categorisation of need/no need for personal assistance. The HACC Functional *Screening* and *Assessment* Instruments and the NHDD do not include questions on communication and can therefore not be compared in terms of the need for assistance with communication.

5.1.4 Domestic tasks

Shopping (ICF code d6200)

Definition and classification

Shopping is classified under Activities and Participation in the ICF, and it is defined at the five digit level of the classification. Shopping is included in ACAP, the HACC Functional Dependency Instruments and the NCSDD, and is defined as an activity.

Personal assistance

The HACC Functional *Screening* and *Assessment* Instruments are the only collections which separately identify the activity of shopping, and their data domains can be mapped to need/no need for personal assistance with shopping.

In the ACAP and NCSDD, shopping is included in the broader group 'activities involved in social and community participation ' and 'domestic activities' respectively, but is not separately identified.

In the remaining collections, the CACP, ABS and NHDD, the activity of shopping is not included.

> ***Comparison***
>
> **Shopping—Item level:**
>
> Dependency with regard to the activity of shopping can be compared only across the HACC Functional *Screening* and *Assessment* Instruments at the item level, using the simple categorisation of need/no need for personal assistance.
>
> The ACAP and NCSDD do not separately identify shopping from the group 'domestic' or 'social participation' activities and can therefore not be compared in terms of the need for assistance with shopping.

Preparing meals (ICF code d630)

Definition and classification

Preparing meals is classified under Activities and Participation in the ICF, and it is defined at the four digit level of the classification. Preparing meals is included in the ACAP data collection, the HACC Functional *Assessment* Instrument, the NCSDD and in the ABS survey, and is defined as an activity.

Personal assistance

The data domains of the HACC Functional *Assessment* Instrument, the ACAP and ABS can be mapped to need/no need for personal assistance with preparing meals.

In the NCSDD, preparing meals is included in the broader group 'domestic activities', but is not separately identified.

In the remaining collections, the HACC Functional *Screening* Instrument, the CACP, and NHDD, the activity of preparing meals is not included.

Comparison

Preparing meals—Item level:

Dependency with regard to the activity of preparing meals can be compared across the HACC Functional *Assessment* Instrument, the ACAP and the ABS at the item level, using the simple categorisation of need/no need for personal assistance.

The NCSDD does not separately identify preparing meals from the group 'domestic activities' and can therefore not be compared in terms of the need for assistance with preparing meals.

Doing housework (ICF code d640)

Definition and classification

Doing housework is classified under Activities and Participation in the ICF, and it is defined at the four digit level of the classification. It includes laundry. Doing housework is included in each of the data collections, except the CACP data collection and the NHDD, and is defined as an activity.

Personal assistance

The HACC Functional *Assessment* Instrument separately identifies housework and laundry, while the HACC Functional *Screening* Instrument, the ACAP, ABS and NCSDD combine these activities. The CACP and NHDD do not include these activities.

The data domains of the HACC Functional *Screening* Instrument, the ACAP and ABS can be mapped to need/no need for personal assistance with doing housework. Similarly, the data domain of the HACC Functional *Assessment* Instrument for both housework and laundry can be mapped to need/no need for personal assistance with these tasks.

In the NCSDD, doing housework is included in the broader group 'domestic activities', but is not separately identified.

Comparison

Doing housework—Item level:

Dependency with regard to the activity of doing housework can be compared across the HACC Functional *Screening* and *Assessment* Instruments, the ACAP and the ABS at the item level, using the simple categorisation of need/no need for personal assistance.

The NCSDD does not separately identify doing housework from the group 'domestic activities' and can therefore not be compared in terms of the need for assistance with housework/laundry.

Caring for household objects (ICF code d650)

Definition and classification

Caring for household objects is classified under Activities and Participation in the ICF, and it is defined at the four digit level of the classification. It includes maintenance and gardening. Caring for household objects is included in the ACAP data collection, the NCSDD and the ABS survey, and is defined as an activity.

Personal assistance

The data domains of the ACAP data collection and ABS can be mapped to need/no need for personal assistance with caring for household objects. In the NCSDD, Caring for household objects is included in the broader group 'domestic activities', but is not separately identified.

Comparison

Caring for household objects—Item level:

Dependency with regard to the activity of caring for household objects can be compared across the ACAP and the ABS at the item level, using the simple categorisation of need/no need for personal assistance.

The HACC Functional *Screening* and *Assessment* Instruments, the CACP and the NHDD do not include questions on caring for household objects and can therefore not be compared in terms of the need for assistance with this activity.

The NCSDD does not separately identify caring for household objects from the group 'domestic activities' and can therefore not be compared in terms of the need for assistance with caring for household objects.

Paperwork/money management (no separate ICF code)

Definition and classification

Paperwork/money management is not included as a distinct activity in the ICF. However, several ICF codes describe relevant activities such as focusing attention (d160), thinking (d163), reading (d166), writing (d170), and economic transactions (d860 and d865). This item is included in the ACAP data collection, the HACC Functional Dependency Instruments and the ABS.

Personal assistance

The data domains of the HACC Functional *Screening* and *Assessment* Instruments, and the ABS, can be mapped to need/no need for personal assistance with paperwork/money management.

In the ACAP, paperwork/money management is included in the broader group 'activities involved in social and community participation ', but is not separately identified.

The remaining collections, the CACP, NHDD, and NCSDD, do not include the item paperwork/money management.

> ***Comparison***
>
> **Paperwork/money management—Item level:**
>
> Dependency with regard to the activity of paperwork/money management can be compared across the HACC Functional *Screening* and *Assessment* Instruments, and the ABS, at the item level, using the simple categorisation of need/no need for personal assistance.
>
> The ACAP collection does not separately identify paperwork/money management from the group 'activities involved in social and community participation' and can therefore not be compared in terms of the need for assistance with paperwork/money management.

5.1.5 Behaviour

Managing behaviour (no separate ICF code or chapter)

Definition and classification

Behaviour is not separately included in the ICF classification, but several codes describe components of behaviour and mental functions relevant to behaviour, e.g. temperament and personal functions (b126), emotional functions (b152), and complex interpersonal interaction (d720). Some behavioural problems can be regarded as a 'health condition', and are classified as such in the ICD-10-AM classification. Managing behaviour is included in the HACC Functional *Assessment* Instrument, the ABS and the NHDD.

Personal assistance

The data domains of the HACC Functional *Assessment* Instrument and the ABS can be mapped to need/no need for personal assistance with managing behaviour. The HACC Functional *Screening* Instrument includes a question on behaviour, but it does not identify the need for assistance with managing behaviour. The NHDD contains an item which, although it identifies the need for personal assistance, includes both behaviour and cognition. The remaining collections, the ACAP, CACP and NCSDD, do not include an item on behaviour.

> ***Comparison***
>
> **Behaviour:**
>
> Dependency with regard to managing behaviour can be compared across the HACC Functional *Assessment* Instrument and the ABS at the item level, using the simple categorisation of need/no need for personal assistance.
>
> The NHDD includes both behaviour and cognition together and can therefore not be compared in terms of the need for assistance with managing behaviour separately.

5.1.6 Cognition

Learning and applying knowledge (ICF Chapter 1, Activities and participation)

Definition and classification

In relation to cognitive functioning, the ICF classification contains a number of codes, which are grouped under the chapter heading 'Learning and applying knowledge', including the following relevant codes: Focusing attention, d160; Thinking, d163; Reading, d166; Writing, d170; Calculating, d172; Solving problems, d175; Making decisions, d177.

Some problems with cognitive functioning are classified in the Body Functions domain of the ICF, and also in the ICD-10-AM classification as a 'health condition', e.g. disorientation or memory loss. The health condition 'dementia' is also classified in the ICD-10-AM classification. Although such coding does not necessarily provide information about a person's dependency, it does provide important information about a person's cognitive functioning.

The HACC Functional Dependency Instruments, the NCSDD and the NHDD include items relating to cognitive functioning. The ACAP data collection does include the data element 'health condition', which allows for the coding of dementia using ICD-10-AM, and the CACP data collection records the item dementia status.

Personal assistance

Only the NCSDD considers dependency in the area of cognition. The NHDD contains an item which identifies need for personal assistance in this area, but it includes both behaviour and cognition which cannot be separately identified. The HACC Functional *Screening* and *Assessment* Instruments include a question on cognitive function but do not identify the need for personal assistance.

Comparison

Cognition:

Dependency with regard to cognition cannot be compared across the collections at the item level.

5.2 Comparisons of activity groupings: comparing self-care, mobility and communication

Self-care

The core activity grouping 'self-care' includes eating, washing oneself, dressing, toileting and managing incontinence. The ACAP and the NCSDD, as mentioned earlier, identify the need for assistance at the self-care level. The CACP, the HACC Functional *Assessment* Instrument and the NHDD identify all these items separately, and they can all be mapped to the level of self-care. This means that comparison of the item 'self-care' across these collections is possible.

It should be noted that some further inconsistency exists in the NCSDD, as the definition of self-care activities includes Health care tasks, which is not consistent with the definitions used in other national standards and data collections.

Self-care and the HACC Functional *Screening* Instrument

In regard to self-care activities, the HACC Functional *Screening* Instrument asks a question about only one item: bathing/showering. The rationale behind asking this particular question is based on the theory that a hierarchy exists amongst ADL activities, and that a person who does not need assistance with bathing/showering is mostly unlikely to need assistance with any of the other self-care tasks. For more information about this issue, please see Section 4.5. If this theory were accepted, the item 'bathing/showering' can be mapped up to the self-care level, and it could be argued that the dependency in terms of self-care in HACC clients screened through this instrument is comparable. If this theory of hierarchy is not accepted in the context of dependency comparisons across programs, then comparability of the HACC Functional *Screening* Instrument at the self-care level does not exist.

Mobility

The core activity grouping 'mobility' includes changing and maintaining body position, moving around in different locations, using transport and lifting and carrying objects. The CACP and the HACC Functional *Assessment* Instrument identify these items separately, and they can all be mapped up to the level of mobility. The ACAP does not separately identify changing and maintaining body position, but it is incorporated in the need for assistance with movement activities. This item, together with moving around in different locations and transport, can be mapped up to the level of 'mobility'.

Comparison of the item 'mobility' across these collections is not possible, due to two definitional differences. Firstly, the question on mobility in the HACC Functional *Assessment* Instrument refers only to mobility indoors. Secondly, the item 'transport' is not included in the CACP, ABS and NCSDD, while in the HACC Functional Instruments, ACAP and the ICF driving is included.

As mentioned earlier, while no specific mention is made in the ABS survey of using stairs or changing and maintaining body position, the assumption has been made that these activities are included in the ABS concept of mobility. They are integral to a person's ability to move around their residence, although using stairs is only applicable in some residences.

Mobility and the HACC Functional *Screening* Instrument

In regard to mobility, the HACC Functional *Screening* Instrument asks a question about only one item: walking. The rationale behind asking this particular question is based on the theory that a hierarchy exists amongst mobility activities, and that a person who does not need assistance with walking is mostly unlikely to need assistance with other forms of mobility. For more information about this issue, see Section 4.5. If this theory were accepted, the item 'walking' could be mapped up to the mobility level, and it could be argued that the dependency in terms of mobility in HACC clients screened through this instrument was comparable. If this theory of hierarchy is not accepted in the context of dependency comparisons across programs, then comparability of the HACC Functional *Screening* Instrument at the mobility level does not exist. It should also be noted that in most collections, the definition of independent mobility includes the independent use of a wheelchair, while the HACC Functional S*creening* Instrument only includes the ability to walk independently.

Communication

The definition of the ABS core activity 'communication' includes the need for assistance with understanding family/friends, being understood by family/friends, understanding

strangers and being understood by strangers. The communication chapter of the ICF also distinguishes between receiving and producing messages, but does not distinguish between communicating with family/friends and strangers. However, the ICF domain 'Environmental Factors' does contain codes that may be used to draw this disctinction.

In the ACAP and CACP data collections and in the NCSDD only the one item, 'communication', is included. In other words, the item level equals the activity group level.

Comparison of the item 'communication' is possible across the ACAP, CACP, ABS and NCSDD. Neither of the HACC Functional Instruments nor the NHDD includes a question on communication, and they are therefore not comparable.

Core activity restriction

The ability to compare clients in terms of their ability to independently carry out core activities depends on the comparability of the items self care, mobility and communication. These items are discussed in detail above.

In short, the major obstacles to the comparability of dependency in core activities are:

- some definitional differences in relation to mobility;
- inability to determine the need for assistance with communication in HACC clients; and
- limited information about HACC clients through the HACC Functional *Screening* Instrument.

The significance of the concept 'core activity restriction' in relation to aged care clients is discussed in Section 4.4.

6 Main findings, recommendations and data issues

6.1 Main findings

The main outcomes of this report's mapping and comparability analysis are listed below. Further detail can be found in Chapter 5 and in Appendix D. It is recommended that these findings be considered together with the outcomes of the comparability assessment described in *Comparability and Consistency of Community Care Meta-data* (Jeffery and Ryan 2002).

It should be recognised that differences in the purpose, the activities and the operational context of the programs affect the appropriateness and relevance of including certain data items in administrative by-product collections. These factors will influence the extent to which differences between data items may need to exist. The findings and recommendations outlined below will need to be considered with these factors in mind, while also recognising the value of adopting a national information and across-program perspective.

In terms of comparability between the three aged and community care programs, ACAP, HACC and CACP, and with the ABS population data, the following differences, inconsistencies and issues were identified:

- **The HACC Functional Dependency Instruments:** the HACC Functional *Assessment* Instrument will provide fairly comprehensive and mostly consistent dependency information about a subset of HACC clients, while the HACC Functional *Screening* Instrument will provide very limited dependency information about all HACC clients. This means that, if national data collection were based on these instruments, comprehensive dependency data would not be available about the full spectrum of HACC clients. (For further discussion, see Sections 4.5 and 5.2, and further text in this chapter.)
- **Self-care and mobility:** while the ACAP data collection includes information on the need for assistance with self-care, it does not separately identify self-care data items such as dressing, eating, etc. Both the HACC Functional *Assessment* Instrument and the CACP data collection do identify the need for assistance with these individual items. ACAP also does not separately identify some of the mobility data items. This means that comparison with ACAP data at the activity level is not possible, and comparison of alternative activity groupings is also not possible (see Section 4.4 for a discussion of activity groups).
- **Core activity restriction:** it is not possible to compare the three programs in terms of the number of clients with a core activity restriction. The main obstacles to the comparability of dependency in core activities are:
  - limited dependency information about all HACC clients (see first dot point);
  - inability to determine the need for assistance with communication in HACC clients; and

- some definitional differences in relation to mobility, in particular: mobility indoors/outdoors, use of a wheelchair/aids, and in/exclusion of driving in transport.

- **Domestic life:** the CACP national collection does not include any information about dependency in domestic tasks. While ACAP and the HACC Functional *Assessment* Instrument do identify dependency in domestic tasks, information for all HACC clients, through the HACC Functional *Screening* Instrument, is limited to two domestic tasks only.
- **'Looking after one's health':** dependency with 'looking after one's health' is identified in ACAP, but no such information is included in the CACP national data collection. Both the HACC Functional *Assessment* and *Screening* Instruments only identify dependency in taking medication.
- **Behaviour:** the HACC Functional *Screening* Instrument collects some information about behavioural problems, while the ACAP data collection includes the item 'health condition', which allows for the identification of behavioural problems through ICD-10 coding. However, only the HACC Functional *Assessment* Instrument identifies dependency information, i.e. need for personal assistance, in relation to managing behaviour.
- **Cognition:** Both HACC Functional Dependency Instruments include questions on cognitive function but they do not identify need for assistance. The ACAP data collection includes the item 'health condition', which allows for the identification of cognitive problems through ICD-10 coding. However, none of the three programs identifies dependency, i.e. need for personal assistance, with regard to cognition. This report does not include an analysis of comparability of environmental factors or information on health conditions. However, it should be noted that the ACAP and CACP national data collections include information on diagnosis of dementia in clients, but this information is not included in the HACC national data collection.
- **Performance and capacity:** the ACAP and CACP Programs differ from the HACC Functional Dependency Instruments and the ABS survey in that they bring into their collection a measure of 'capacity'. In these two programs, if the client's need for assistance can be met by their independent use of aids and equipment, they are recorded as not needing assistance from another person, even if in the current environment the client does not (yet) have access to such aids or equipment (see Section 1.7).
- **Aids and equipment:** while the ACAP and CACP data dictionaries both clearly define whether the independent use of aids and equipment is included in the coding, this is not explicitly stated in the HACC Functional Dependency Instruments. The coding in question 7 in the HACC Functional *Screening* Instrument records a person who uses aids such as a walker or crutches in the same category as someone who requires personal assistance, thus making the need for personal assistance indistinguishable.

6.2 Recommendations

The comparability analysis in this report has revealed some minor as well as major differences and inconsistencies in dependency information across the ACAP, HACC and CACP programs. In the analysis, decisions had to be made about what level of precision should be applied. Some inconsistencies are clearly important and could have a distorting impact on the data, whereas for some of the smaller inconsistencies, though they may affect

the data in a minor way, this effect is likely to be insignificant. Such minor inconsistencies have not been included in these recommendations.

The recommended modifications and other data issues outlined below are based on those inconsistencies that are likely to have a significant impact on the ability to compare dependency data.

Recommended modifications

- In order to enable comparison between community aged care clients in the ACAP, HACC and CACP programs in terms of their core activity restriction, i.e. self-care, mobility and communication, the following changes would need to be made to data collections/instruments:
  - The HACC Functional *Assessment* Instrument would need to include mobility outside the person's residence in its item 'mobility'. In the proposed instrument,mobility has been defined as mobility indoors only.
  - The HACC Functional *Screening* and *Assessment* Instruments would need to include a question on communication. The proposed instruments do not include communication in any way.
  - More comprehensive information about dependency in self-care, mobility and communication in all HACC clients would need to be collected. See 'Other data issues' below for comment on the HACC Functional *Screening* Instrument.
- Dependency in taking medication is included in both HACC Functional Dependency Instruments, but not in the ACAP and CACP national collections. Consideration should be given to whether this information might be of interest, both within these programs and in terms of the need to compare across programs.
- Aids and equipment: the ACAP and CACP data dictionaries both clearly define whether the independent use of aids and equipment is included in the coding. It is recommended that if or when a data element on HACC clients' activity limitations is included in the HACC MDS, the independent use of aids and equipment be clearly defined/identified in the relevant version of the HACC data dictionary.
- Aids and equipment: it is recommended that the data domain of question 7 of the HACC Functional *Screening* Instrument be revised. To be able to clearly distinguish dependency on personal assistance, the data domain needs to contain separate codes for the use of a walker or crutches and the help of a person. Also in regard to question 7, it is recommended that information on mobility through the independent use of a wheelchair be collected as well, as this will improve comparability with other data collections.
- In relation to cognition, it is recommended that consideration be given to the inclusion of a data item on (diagnosed) dementia status in the HACC MDS. While such an item cannot be considered a dependency measure, it would fill a gap in the availability of information about aged and community care clients' cognitive function and improve comparability in this area across the three programs. Alternatively, or perhaps as well, all three programs under discussion in this report may want to consider collecting information on the need for assistance with regard to cognitive functioning, if the identification of *dependency* in this area is desired.

Other modifications for consideration

- In order to enable comparison between community aged care clients in the ACAP, HACC and CACP programs in terms of their dependency with individual self-care activities, the ACAP data collection would need to include these individual data items in its MDS. This would also enable comparison of activity groupings other than self-care, mobility and communication (see examples in Section 4.4).
- Mobility in each of the three aged and community care programs, the ICF and the various national standards is made up of different data items or 'building blocks', producing a high level of inconsistency across all collections and standards. With inconsistency even amongst the national standards, the ICF offers a classification that may form a basis for improved consistency among the programs as well as the national standards. This report makes use of the ICF codes that are most appropriate for the activities/data items described in the data collections included in this project. It is suggested that, in the context of future MDS revisions, consideration be given to the ICF and the ICF codes used here to aid the description and categorisation of mobility.
- The CACP national data collection does not include any data items related to domestic life, either as separate items or as a grouping. Inclusion of dependency with domestic tasks in the CACP data collection would enable comparison across all three programs in this area.

Other data issues for consideration

Consideration may need to be given to the fact that the HACC Functional *Screening* Instrument, while it may be a useful instrument in the service provision context, will not provide comprehensive national information about dependency in HACC clients. It will, in its current form, provide data that will only enable very limited comparisons of HACC clients with other aged and community care clients.

Comparability of core activity restriction in clients across the programs and with ABS population data is affected by the lack of consistency in the definition of transport. The HACC Functional *Assessment* Instrument and the ACAP data collection both include the use of public transport and driving in the item 'transport', which results in driving being included when transport is mapped up to mobility. CACP and the ABS include the use of public transport, but not driving, while the ICF does include driving in the chapter 'Mobility'. Therefore, no recommendation is made in this report on the inclusion or exclusion of driving. In order to become consistent with the ICF, the CACP data collection would need to include driving at some time in the future. However, it is acknowledged that such a change would decrease consistency with ABS population data.