

Person—informal carer existence indicator, code N

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Person—informal carer existence indicator, code N

Identifying and definitional attributes

Metadata item type:	Data Element
Short name:	Informal carer existence indicator
Synonymous names:	Informal carer availability, Informal carer existence flag, Carer arrangements (informal)
METEOR identifier:	320939
Registration status:	Community Services (retired) , Standard 29/04/2006 Disability , Superseded 29/02/2016 Health , Superseded 17/10/2018
Definition:	Whether a person has an informal carer , as represented by a code.
Data Element Concept:	Person—informal carer existence indicator
Value Domain:	Yes/no/not stated/inadequately described code N

Value domain attributes

Representational attributes

Representation class:	Code	
Data type:	Boolean	
Format:	N	
Maximum character length:	1	
	Value	Meaning
Permissible values:	1	Yes
	2	No
Supplementary values:	9	Not stated/inadequately described

Collection and usage attributes

Guide for use:	CODE 9 Not stated/inadequately described This code is not for use in primary data collections.
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Source and reference attributes

Submitting organisation:	Australian Institute of Health and Welfare
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Data element attributes

Collection and usage attributes

Guide for use:

Informal carers may include those people who receive a pension or benefit for their caring role and people providing care under family care agreements. Excluded from the definition of informal carers are volunteers organised by formal services and paid workers.

This metadata item is purely descriptive of a client's circumstances. It is not intended to reflect whether the informal carer is considered by the service provider to be capable of undertaking the caring role. The expressed views of the client and/or their carer should be used as the basis for determining whether the client is recorded as having an informal carer or not.

When asking a client whether they have an informal carer, it is important for agencies or establishments to recognise that a carer does not always live with the person for whom they care. That is, a person providing significant care and assistance to the client does not have to live with the client in order to be called an informal carer.

Collection methods:

Agencies or establishments and service providers may collect this item at the beginning of each service episode and /or assess this information at subsequent assessments.

Some agencies, establishments/providers may record this information historically so that they can track changes over time. Historical recording refers to the practice of maintaining a record of changes over time where each change is accompanied by the appropriate date.

Examples of questions that have been used for data collection include:

Home and Community Care NMDS

'Do you have someone who helps look after you?'

Commonwealth State/Territory Disability Agreement NMDS

'Does the service user have an informal carer, such as [family](#) member, friend or neighbour, who provides care and assistance on a regular and sustained basis?'

Comments:

Recent years have witnessed a growing recognition of the critical role that informal support networks play in caring for frail older people and people with disabilities within the community. Not only are informal carers responsible for maintaining people with often high levels of functional dependence within the community, but the absence of an informal carer is a significant risk factor contributing to institutionalisation. Increasing interest in the needs of carers and the role they play has prompted greater interest in collecting more reliable and detailed information about carers and the relationship between informal care and the provision of and need for formal services.

This definition of informal carer is not the same as the Australian Bureau of Statistics (ABS) definition of principal carer, 2003 Survey of Disability, Ageing and Carers and primary carer used in the 1998 survey. The ABS definitions require that the carer has or will provide care for a certain amount of time and that they provide certain types of care.

The ABS defines a primary carer as a person of any age who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self care). This may not be appropriate for community services agencies wishing to obtain information about a person's carer regardless of the amount of time that care is for, or the types of care provided.

Information such as the amount of time for which care is provided can of course be collected separately but, if it were not needed, it would place a burden on service providers.

Source and reference attributes

Origin: Australian Institute of Health and Welfare
National Health Data Committee
National Community Services Data Committee

Reference documents: Australian Bureau of Statistics (ABS) 1993 Disability, Ageing and Carers Survey and 2003 Survey of Disability, Ageing and Carers.

Australian Institute of Health and Welfare (2005) Commonwealth State/Territory Disability Agreement National Minimum Data Set collection (CSTDA NMDS) Data Guide: 2005-06.

National HACC Minimum Data Set User Guide Version 2 July 2005. Home and Community Care (HACC) Program.

Relational attributes

Related metadata references: Supersedes [Person \(requiring care\)—carer availability status, code N Community Services \(retired\)](#), Superseded 29/04/2006
[Health](#), Superseded 04/07/2007

Has been superseded by [Person—informal carer existence indicator, yes/no/not stated/inadequately described code N Disability](#), Standard 29/02/2016
[Health](#), Standard 17/10/2018

Implementation in Data Set Specifications: [Cardiovascular disease \(clinical\) DSS Health](#), Superseded 22/12/2009
DSS specific information:

Informal carers are now present in 1 in 20 households in Australia (Schofield HL, Herrman HE, Bloch S, Howe A and Singh B. ANZ J PubH. 1997) and are acknowledged as having a very important role in the care of stroke survivors (Stroke Australia Task Force. National Stroke Strategy. NSF; 1997) and in those with end-stage renal disease.

Absence of a carer may also preclude certain treatment approaches (for example, home dialysis for end-stage renal disease). Social isolation has also been shown to have a negative impact on prognosis in males with known coronary artery disease with several studies suggesting increased mortality rates in those living alone or with no confidant.

[Cardiovascular disease \(clinical\) DSS Health](#), Superseded 01/09/2012
DSS specific information:

Informal carers are now present in 1 in 20 households in Australia (Schofield HL, Herrman HE, Bloch S, Howe A and Singh B. ANZ J PubH. 1997) and are acknowledged as having a very important role in the care of stroke survivors (Stroke Australia Task Force. National Stroke Strategy. NSF; 1997) and in those with end-stage renal disease.

Absence of a carer may also preclude certain treatment approaches (for example, home dialysis for end-stage renal disease). Social isolation has also been shown to have a negative impact on prognosis in males with known coronary artery disease with several studies suggesting increased mortality rates in those living alone or with no confidant.

[Cardiovascular disease \(clinical\) NBPDS Health](#), Superseded 17/10/2018
DSS specific information:

Informal carers are now present in 1 in 20 households in Australia (Schofield HL, Herrman HE, Bloch S, Howe A and Singh B. ANZ J PubH. 1997) and are acknowledged as having a very important role in the care of stroke survivors (Stroke Australia Task Force. National Stroke Strategy. NSF; 1997) and in those with end-stage renal disease.

Absence of a carer may also preclude certain treatment approaches (for example,

home dialysis for end-stage renal disease). Social isolation has also been shown to have a negative impact on prognosis in males with known coronary artery disease with several studies suggesting increased mortality rates in those living alone or with no confidant.

[Commonwealth State/Territory Disability Agreement NMDS - 1 July 2006](#)
[Community Services \(retired\)](#), Superseded 14/12/2008

DSS specific information:

It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.

It is also recognised that the roles of parent and carer, particularly in the case of children, are difficult to distinguish. Parents of children should generally be recorded as a carer if they provide more care to their child than would be typical of the care provided to a child of the same age without a disability.

[Commonwealth State/Territory Disability Agreement NMDS \(July 2008\)](#)
[Community Services \(retired\)](#), Superseded 11/11/2009

DSS specific information:

It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.

It is also recognised that the roles of parent and carer, particularly in the case of children, are difficult to distinguish. Parents of children should generally be recorded as a carer if they provide more care to their child than would be typical of the care provided to a child of the same age without a disability.

[Disability Services NMDS 2009-10](#)
[Community Services \(retired\)](#), Superseded 15/12/2011

Implementation start date: 01/07/2009

DSS specific information:

It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.

It is also recognised that the roles of parent and carer, particularly in the case of children, are difficult to distinguish. Parents of children should generally be recorded as a carer if they provide more care to their child than would be typical of the care provided to a child of the same age without a disability.

[Disability Services NMDS 2010-11](#)
[Community Services \(retired\)](#), Superseded 15/12/2011

Implementation start date: 01/07/2010

DSS specific information:

It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.

It is also recognised that the roles of parent and carer, particularly in the case of children, are difficult to distinguish. Parents of children should generally be recorded as a carer if they provide more care to their child than would be typical of the care provided to a child of the same age without a disability.

[Disability Services NMDS 2011-12](#)
[Community Services \(retired\)](#), Superseded 13/03/2013

Implementation start date: 01/07/2011

DSS specific information:

It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.

It is also recognised that the roles of parent and carer, particularly in the case of children, are difficult to distinguish. Parents of children should generally be recorded as a carer if they provide more care to their child than would be typical of the care provided to a child of the same age without a disability.

Disability Services NMDS 2012-14

Community Services (retired), Standard 13/03/2013

Implementation start date: 01/07/2012

Implementation end date: 30/06/2014

DSS specific information:

In the DS NMDS this data item refers to whether someone, such as a family member, friend or neighbour, has been identified as providing regular and sustained care and assistance to the person requiring support.

Informal carers include those people who receive a pension or benefit for their caring role but do not include paid or volunteer carers organised by formal services. This includes a host family or foster care situation where the family is paid to care for a service user.

A carer is someone who provides a significant amount of care and/or assistance to the person on a regular and sustained basis. 'Regular' and 'sustained' in this instance means that care or assistance has to be ongoing, or likely to be ongoing for at least 6 months.

Excluded from the definition of carers are paid workers or volunteers organised by formal services (including paid staff in funded group homes).

It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.

It is also recognised that the roles of parent and carer, particularly in the case of children, are difficult to distinguish. Carers of children may consider they are a carer (as well as a parent) if they provide more care to their child than would be typical of the care provided to a child of the same age without a disability.

This data item is purely descriptive of a service user's circumstances. It is not intended to reflect whether the carer is considered by the funded agency capable of undertaking the caring role.

In line with this, the expressed views of the service user and/or their carer should be used as the basis of determining whether the service user is recorded as having a carer or not.

When asking a service user about the availability of a carer, it is important to recognise that a carer does not always live with the person for whom they care. That is, a person providing significant care and assistance to the person may not live with the person in order to be called a carer.

Disability Services NMDS 2014-15

Disability, Superseded 29/02/2016

Implementation start date: 01/07/2014

Implementation end date: 30/06/2015

DSS specific information:

In the Disability Services Minimum Data Set (DS NMDS), this data item refers to whether someone, such as a family member, friend or neighbour, has been identified as providing regular and sustained care and assistance to the person requiring support.

Informal carers include those people who receive a pension or benefit for their caring role but do not include paid or volunteer carers organised by formal services. This includes a host family or foster care situation where the family is paid to care for a service user.

A carer is someone who provides a significant amount of care and/or assistance to the person on a regular and sustained basis. 'Regular' and 'sustained' in this instance means that care or assistance has to be ongoing, or likely to be ongoing for at least 6 months.

Excluded from the definition of carers are paid workers or volunteers organised by formal services (including paid staff in funded group homes).

It is recognised that two or more people may equally share the caring role (e.g. mother and father) however, for the purposes of this collection, characteristics are only requested for one of these carers.

It is also recognised that the roles of parent and carer, particularly in the case of children, are difficult to distinguish. Carers of children may consider they are a carer (as well as a parent) if they provide more care to their child than would be typical of the care provided to a child of the same age without a disability.

This data item is purely descriptive of a service user's circumstances. It is not intended to reflect whether the carer is considered by the [funded agency](#) capable of undertaking the caring role.

In line with this, the expressed views of the service user and/or their carer should be used as the basis of determining whether the service user is recorded as having a carer or not.

When asking a service user about the availability of a carer, it is important to recognise that a carer does not always live with the person for whom they care. That is, a person providing significant care and assistance to the person may not live with the person in order to be called a carer.

[Home and Community Care MDS 2009](#)

[Community Services \(retired\)](#), Recorded 16/11/2009

Implementation start date: 11/05/2006

DSS specific information:

This data element should be recorded at the beginning of each HACC service episode. The agency should also assess the currency of this information at subsequent assessments/re-assessments within any given HACC service episode and should update the agency's record of the client's Informal carer availability if necessary.

Reporting requirements:

Agencies are required to report the most recent Informal carer availability that the agency has recorded for the client.

Information provided by the agency about the person's Informal carer availability will be considered to be at least as up to date as the Date of last update reported for the person. This is in line with the request that agencies assess and update the information they have about the client's Informal carer availability at the beginning of each HACC service episode as well as at subsequent assessments/re-assessments within any given HACC service episode.

If the agency's system or records do not provide sufficient information to accurately report on this data element, the agency should use code 9 Not stated/inadequately described.

The data element Informal carer availability, uses the same categories as the NCSDD V3, 2005.

The National Health Data Dictionary (NHDD) includes a data element named Carer Availability which is used within the Community Nursing Minimum Data Set (CNMDSA). However, there are significant differences in the CNMDSA data element and the HACC MDS data element of the same name. These differences

relate to differences in the information needed (and considered appropriate for collection) by community nurses and that needed (and considered appropriate for collection) by the broader range of HACC-funded agencies. There are also differences in the scope of information collected through this data element in both data sets. The HACC MDS includes a separate data element Carer residency status which provides information about whether the person identified as the main or primary Carer lives with the person with whom they care or not. This information is included within the classification used by the CNMDSA Carer Availability data element.

The CNMDSA data element is also intended to relate more directly to the agency's assessment process. As such, it relies on the service provider's assessment as to whether a client is in need of a Carer, and the service provider's assessment as to whether a 'potential' Carer is capable or willing to undertake the caring role. While this may be appropriate to a community nursing context, it is considered inappropriate to apply these same assumptions and expectations to the broader HACC field.

Future developments in the HACC MDS and the CNMDSA may need to see the data elements converge more; or may require a much clearer distinction between the two given their distinct and largely incompatible intentions (i.e. client reported availability versus a service provider assessment of availability, need and adequacy).

The resolution of these inconsistencies will be a priority for future developments of the HACC MDS and the CNMDSA. The resolution of such inconsistencies is particularly important as the HACC program is a major source of funding for many community nursing agencies and these agencies are required to report on the data elements included in the HACC MDS.

Implementation in Indicators:

Used as Numerator

[National Disability Agreement: g-Labour force participation rate for carers aged 15-64 of people with disability, 2010](#)

[Community Services \(retired\)](#), Superseded 15/12/2011

[National Disability Agreement: h-Proportion of carers of people with disability accessing support services to assist in their caring role \(h-interim\), 2010](#)

[Community Services \(retired\)](#), Superseded 15/12/2011

[National Disability Agreement: h-Proportion of carers of people with disability accessing support services to assist in their caring role \(h-interim\), 2011](#)

[Community Services \(retired\)](#), Superseded 05/03/2012

[National Disability Agreement: h-Proportion of carers of people with disability accessing support services to assist in their caring role \(h-interim\), 2012](#)

[Community Services \(retired\)](#), Superseded 23/05/2013

Used as Denominator

[National Disability Agreement: g-Labour force participation rate for carers aged 15-64 of people with disability, 2010](#)

[Community Services \(retired\)](#), Superseded 15/12/2011

[National Disability Agreement: h-Proportion of carers of people with disability accessing support services to assist in their caring role \(h-interim\), 2010](#)

[Community Services \(retired\)](#), Superseded 15/12/2011