Person—informal carer existence indicator, yes/no/not stated/inadequately described code N

Exported from METEOR (AIHW's Metadata Online Registry)

Person—informal carer existence indicator, yes/no/not stated/inadequately described 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:	621393
Registration status:	Disability, Standard 29/02/2016 Health!, Standard 17/10/2018
Definition:	An indicator of 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:	Number	
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.

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 (HACC) MDS

‘Do you have someone who helps look after you?’

Disability Services 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 carer or primary carer used in the Survey of Disability, Ageing and Carers (SDAC). 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. In SDAC, a carer is defined as a person of any age who provides any informal assistance, in terms of help or supervision, to an older person or someone who has a disability or a long-term health condition. This assistance has been, or is likely to be, ongoing for at least six months. A primary carer is someone aged 15 years and over who provides the most informal assistance to a person with disability with one or more of the core activities of mobility, self-care and communication. These definitions 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

Submitting organisation: Australian Institute of Health and Welfare

Relational attributes

Related metadata references:

Supersedes Person—informal carer existence indicator, code N
Community Services (retired), Standard 29/04/2006
Disability, Superseded 29/02/2016
Health!, Superseded 17/10/2018

Implementation in Data Set Specifications:

Cardiovascular disease (clinical) NBPDS
Health!, Standard 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.

Disability Services NMDS 2015–16
Disability, Superseded 28/09/2016
Implementation start date: 01/07/2015
Implementation end date: 30/06/2016
DSS specific information:

In the Disability Services Minimum Data Set (DS NMDS), this data element 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 **service user**.

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 2016–17
Disability, Superseded 15/12/2017

Implementation start date: 01/07/2016
Implementation end date: 30/06/2017
DSS specific information:

In the Disability Services National Minimum Data Set (DS NMDS), this data element 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 **service user**.

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.

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Disability Services NMDS 2017–18
    Disability, Superseded 05/07/2019
Implementation start date: 01/07/2017
Implementation end date: 30/06/2018
DSS specific information:

In the Disability Services National Minimum Data Set (DS NMDS), this data element 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 **service user**.

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 (for example, 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 element 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.

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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 2018–19
  Disability, Standard 05/07/2019
Implementation start date: 01/07/2018
Implementation end date: 30/06/2019
DSS specific information:

In the Disability Services National Minimum Data Set (DS NMDS), this data element 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 **service user**.

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.

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