Informal carer availability

Important note: This is an archived metadata standard from the AIHW Knowledgebase. For current metadata standards and related information please access METeOR, the AIHW's Metadata Online Registry at http://meteor.aihw.gov.au

Identifying and Definitional Attributes

Data Dictionary: Int. NCSDD & NHDD

Knowledgebase ID: 002003 Version number: 4

Metadata type: DATA ELEMENT

Registration NCSIMG & NHIMG Admin status: SUPERSEDED

Authority: Effective date: 01-MAR-05

Definition: Whether someone, such as a family member, friend or neighbour,

has been identified as providing regular and sustained informal care

and assistance to the person requiring care.

Carers include those people who receive a pension or benefit for their caring role but does not include paid or volunteer carers

organised by formal services.

Context: Ageing, disability and health

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.

Relational and Representational Attributes

Datatype: Numeric

Representational CODE

form:

Representation N

layout:

Minimum Size: 1
Maximum Size: 1

Data Domain: 1 Has a carer

2 Has no carer

Guide For Use: This data element is purely descriptive of a client's circumstances. It is not intended to reflect whether the carer is considered by the service provider to be capable of undertaking the caring role. In line with this, 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 a carer or not.

> A carer is someone who provides a significant amount of care and/or assistance to the person on a regular and sustained basis. Excluded from the definition of carers are paid workers or volunteers organised by formal services (including paid staff in funded group houses).

> When asking a client about the availability of a 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 a carer. The availability of a carer should also be distinguished from living with someone else. Although in many instances a coresident will also be a carer, this is not necessarily the case. The data element Living arrangement is designed to record information about person(s) with whom the client may live.

Collection Methods: Agencies or establishments and service providers may collect this item at the beginning of each service episode and also assess this information at subsequent assessments or re-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.

Related metadata: supersedes the NCSDD data element Carer availability version 1 relates to the NCSDD data element Carer co-residency version 1 relates to the NCSDD data element Relationship of carer to care recipient version 1

> relates to the NCSDD data concept Family version 2 supersedes the NHDD data element Carer availability version 3 relates to the NCSDD data concept Volunteer version 2 relates to the NCSDD data element Activity - level of difficulty version 2

Administrative Attributes

Source Document:

Source Organisation: Australian Institute of Health and Welfare

National Health Data Committee and National Community

Services Data Committee

Comments: This metadata item is common to both the National Community Services Data Dictionary and the National Health Data Dictionary. This definition of 'Informal carer availability' is not the same as the ABS definition of 'Principal carer', 1993 Disability, Ageing and Carers Survey 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. This may not be appropriate for agencies or establishments 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.

NHDD specific DSS Cardiovascular disease (clinical):

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.

Data Element Links

Information Model Entities linked to this Data Element

NCSIM Carer role

Data Agreements which include this Data Element

DSS - Cardiovascular disease (clinical) From 02-Sep-03 to