

AUSTRALIAN INSTITUTE FOR SOCIAL RESEARCH

EVALUATION OF THE DEMONSTRATION DAY RESPITE PILOT IN RESIDENTIAL AGED CARE FACILITIES INITIATIVE

REPORT OF CLIENT PATHWAY ANALYSIS

REPORT PREPARED FOR:

THE DEPARTMENT OF HEALTH AND AGEING

RESPITE FOR CARERS SECTION, OFFICE FOR AN AGEING AUSTRALIA, AGEING AND AGED
CARE DIVISION

PREPARED BY MS NAOMI GUIVER WITH DR KATE BARNETT

8TH JUNE 2011



AISR
Informing Decisions

TABLE OF CONTENTS

1	EXECUTIVE SUMMARY	1
2	INTRODUCTION	3
2.1	CONTEXT FOR THE CLIENT PATHWAY ANALYSIS	3
2.1.1	<i>The DDR Initiative</i>	3
2.1.2	<i>Evaluation of the DDR Initiative.....</i>	3
2.1.3	<i>Distinguishing features of the DDR evident from the Evaluation.....</i>	4
2.1.4	<i>The need for a Client Pathway Analysis</i>	4
2.2	RELEVANT FINDINGS FROM THE RESEARCH LITERATURE	5
2.2.1	<i>The Pathways in Aged Care (PIAC) Project.....</i>	5
2.2.2	<i>Key findings from the PIAC research</i>	5
2.2.3	<i>Findings relating to residential respite care.....</i>	7
2.2.4	<i>Findings relating to residential respite and dementia</i>	8
3	METHOD.....	10
3.1	DESIGN OF METHODOLOGY	10
3.2	QUESTIONNAIRE DESIGN.....	10
3.3	RECRUITMENT OF SITES	11
3.4	SURVEY IMPLEMENTATION AND MONITORING.....	12
3.5	DATA CAPTURE AND STORAGE	12
3.6	DATA ANALYSIS.....	13
4	FINDINGS.....	14
4.1	THE SAMPLE.....	14
4.1.1	<i>Participation by site</i>	14
4.1.2	<i>Location of respondents.....</i>	16
4.1.3	<i>Demographic characteristics of carers and care recipients</i>	17
4.1.4	<i>Health and wellbeing of carers and care recipients</i>	20
4.1.5	<i>Duration of involvement with the DDR Service</i>	21
4.1.6	<i>Characteristics of respondents who had exited the DDR service</i>	21
4.1.7	<i>Comparison of the sample against other sources from the Evaluation</i>	23
4.2	ENTRY PATHWAYS	26
4.2.1	<i>Becoming aware of the DDR service</i>	26
4.2.2	<i>Time spent on a waiting list for the DDR service.....</i>	26
4.2.3	<i>Government packages and programs used before entering the DDR service</i>	27
4.2.4	<i>Relationship between packages/programs and means of entry to DDR.....</i>	28
4.2.5	<i>Types of services used before entering the DDR service</i>	30
4.2.6	<i>Additional services needed prior to entering the DDR service</i>	32
4.3	PROGRAMS, PACKAGES AND SERVICES USED DURING INVOLVEMENT WITH DDR	33
4.3.1	<i>Government packages and programs used during involvement with DDR.....</i>	33
4.3.2	<i>Types of services used in combination with DDR</i>	34
4.3.3	<i>Additional services needed while using the DDR service.....</i>	37
4.4	EXIT PATHWAYS	38
4.4.1	<i>Reasons for exit.....</i>	38
4.4.2	<i>Broad exit pathways</i>	39
4.4.3	<i>Government packages and programs used after exiting DDR</i>	39
4.4.4	<i>Types of services used after exiting DDR.....</i>	41
4.4.5	<i>Additional services needed after exiting DDR</i>	45
4.5	ENTIRE PATHWAYS	45
4.5.1	<i>Program/package pathways.....</i>	45
4.5.2	<i>Respite service pathways.....</i>	50

5	REFERENCES	55
6	APPENDIX – THE QUESTIONNAIRE	56

LIST OF TABLES

TABLE 1: DESCRIPTION OF THE 14 KEY PATHWAYS IDENTIFIED BY THE PIAC PROJECT	6
TABLE 2: DAY RESPITE SERVICES WHICH PARTICIPATED IN THE CLIENT PATHWAY SURVEY	11
TABLE 3: NUMBER OF RESPONDENTS FROM EACH PARTICIPATING SITE	14
TABLE 4: HEALTH CONDITIONS AND DIFFICULTIES REPORTED FOR CARE RECIPIENTS	20
TABLE 5: COMPARISON OF DEMOGRAPHIC CHARACTERISTICS OF CARERS AND CARE RECIPIENTS ACROSS DDR DATA SOURCES	24
TABLE 6: COMPARISON OF HEALTH & SERVICE USAGE CHARACTERISTICS OF CARERS AND CARE RECIPIENTS ACROSS DATA SOURCES.....	25
TABLE 7: HOW CARERS FIRST BECAME AWARE OF THE DDR SERVICE	26
TABLE 8: REASONS FOR EXIT FROM THE DDR SERVICE	38
TABLE 9: RATES OF EXIT TO FULL TIME RESIDENTIAL CARE, BY TYPE OF CARE.....	42
TABLE 10: SUMMARY OF GOVERNMENT PROGRAM/PACKAGE USE ACROSS THE CARER JOURNEY	46
TABLE 11: SUMMARY OF THE USE OF NON-DDR RESPITE SERVICES ACROSS THE CARER JOURNEY.....	50

LIST OF FIGURES

FIGURE 1: RESPONSE RATES BY SITE	15
FIGURE 2: STATE DISTRIBUTION OF RESPONDENTS.....	16
FIGURE 3: REMOTENESS AREA DISTRIBUTION OF RESPONDENTS	16
FIGURE 4: SEX OF CARERS AND CARE RECIPIENTS.....	17
FIGURE 5: AGE PROFILE OF CARERS AND CARE RECIPIENTS.....	17
FIGURE 6: MARITAL STATUS OF CARERS (LEFT) AND CARE RECIPIENTS (RIGHT).....	18
FIGURE 7: COUNTRY OF BIRTH OF CARERS (LEFT) AND CARE RECIPIENTS (RIGHT).....	18
FIGURE 8: MAIN LANGUAGE SPOKEN AT HOME BY CARERS (LEFT) AND CARE RECIPIENTS (RIGHT)	19
FIGURE 9: LIVING ARRANGEMENTS (LEFT) AND RELATIONSHIP (RIGHT) OF CARER AND CARE RECIPIENT.....	19
FIGURE 10: CARERS’ DESCRIPTION OF THEIR CURRENT PHYSICAL HEALTH (LEFT) AND EMOTIONAL AND MENTAL WELL BEING (RIGHT) ..	20
FIGURE 11: DURATION OF INVOLVEMENT WITH THE DDR SERVICE	21
FIGURE 12: TIME SINCE EXIT FROM THE DDR SERVICE	22
FIGURE 13: DURATION OF INVOLVEMENT WITH THE DDR SERVICE, BY EXIT STATUS.....	22
FIGURE 14: TIME SPENT ON A WAITING LIST FOR THE DDR SERVICE.....	27
FIGURE 15: GOVERNMENT PROGRAMS AND PACKAGES USED BEFORE BECOMING INVOLVED WITH THE DDR SERVICE	28
FIGURE 16: COMBINATIONS OF PROGRAMS AND PACKAGES USED BEFORE BECOMING INVOLVED WITH THE DDR SERVICE	28
FIGURE 17: MEANS OF ENTRY INTO THE DDR SERVICE IN THE CONTEXT OF GOVERNMENT PROGRAM/PACKAGE USE.....	29
FIGURE 18: TYPES OF SERVICES USED BEFORE ENTERING THE DDR SERVICE, RANKED FROM MOST TO LEAST COMMON	31
FIGURE 19: COMBINATIONS OF RESPITE SERVICES USED BEFORE ENTERING THE DDR SERVICE.....	32
FIGURE 20: USE OF GOVERNMENT PROGRAMS/PACKAGES WHILE INVOLVED WITH DDR COMPARED WITH PRIOR TO DDR	33
FIGURE 21: NATURE OF CHANGE IN USE OF GOVERNMENT PACKAGES/PROGRAMS AFTER ENTERING DDR	34
FIGURE 22: COMBINATIONS OF PROGRAMS AND PACKAGES USED WHILE INVOLVED WITH DDR COMPARED WITH PRIOR TO DDR.....	34
FIGURE 23: BROAD CHANGES IN SERVICE ENGAGEMENT AFTER ENTERING DDR	35
FIGURE 24: CHANGE IN ENGAGEMENT WITH EACH SERVICE TYPE AFTER ENTERING DDR (RANKED FROM GREATEST TO LEAST INCREASE)	36
FIGURE 25: COMBINATIONS OF OTHER RESPITE SERVICES USED WHILE INVOLVED WITH THE DDR SERVICE.....	37
FIGURE 26: DIAGRAM SHOWING BROAD EXIT PATHWAYS FOR THE SAMPLE	39

FIGURE 27: COMBINATIONS OF GOVERNMENT PACKAGES/PROGRAMS USED AFTER EXIT FROM DDR, BY EXIT SUBGROUP	40
FIGURE 28: GOVERNMENT PROGRAMS/PACKAGES USED AFTER EXITING DDR COMPARED WITH DURING DDR, BY EXIT SUBGROUP....	41
FIGURE 29: TYPES OF SERVICES USED AFTER EXIT FROM DDR, RANKED FROM MOST TO LEAST COMMON	42
FIGURE 30: BROAD CHANGES IN SERVICE ENGAGEMENT AFTER EXITING DDR, BY EXIT SUBGROUP	43
FIGURE 31: SERVICE PROFILE OF CASES WHERE THE CARE RECIPIENT WAS STILL LIVING AFTER DDR EXIT	44
FIGURE 32: GOVERNMENT PROGRAM/PACKAGE USE PATHWAYS FOR THOSE WHO WERE <i>ONLY USING HACC/VHC</i> BEFORE ENTERING THE DDR SERVICE	47
FIGURE 33: GOVERNMENT PROGRAM/PACKAGE USE PATHWAYS FOR THOSE WHO WERE USING <i>PACKAGE(S) +/- HACC/VHC</i> BEFORE ENTERING THE DDR SERVICE	48
FIGURE 34: GOVERNMENT PROGRAM/PACKAGE USE PATHWAYS FOR THOSE WHO WERE <i>NOT USING ANY PROGRAMS OR PACKAGES</i> BEFORE ENTERING THE DDR SERVICE	49
FIGURE 35: RESPITE SERVICE PATHWAYS FOR THOSE WHO WERE <i>ONLY USING ACTIVITY GROUPS/CENTRE-BASED DAY CARE</i> BEFORE ENTERING THE DDR SERVICE	51
FIGURE 36: RESPITE SERVICE PATHWAYS FOR THOSE WHO WERE <i>ONLY USING IN HOME, OVERNIGHT AND/OR RESIDENTIAL RESPITE</i> BEFORE ENTERING THE DDR SERVICE	52
FIGURE 37: RESPITE SERVICE PATHWAYS FOR THOSE WHO WERE USING A <i>COMBINATION OF ACTIVITY GROUPS/CENTRE BASED DAY CARE AND IN HOME/OVERNIGHT/RESIDENTIAL RESPITE</i> BEFORE DDR.....	53
FIGURE 38: RESPITE SERVICE PATHWAYS FOR THOSE WHO <i>DID NOT USE ANY RESPITE SERVICES</i> BEFORE ENTERING THE DDR SERVICE ..	54

1 EXECUTIVE SUMMARY

A Client Pathway Survey was conducted in early 2011 as part of the Evaluation of the *Demonstration Sites for Day Respite in Residential Aged Care Facilities* (DDR) initiative. The survey gathered information on the pathways taken by clients into and out of the DDR service. Fourteen of the 31 DDR sites volunteered to be part of the survey.

Data was collected for a total of 232 carers. The sample was representative of the broader population of carers and care recipients involved in the DDR program, and included clients who had exited the program as well as those who were still using the program at the time of the survey.

The main findings from the pathway analysis are outlined below.

Entry pathways

In terms of pathways into the DDR service, almost two thirds of carers indicated that they and/or the care recipient had used *at least one* type of Government program/package (HACC, VHC, CACP, EACH, EACHD) prior to entering the DDR service. The most commonly used programs/packages prior to entry to DDR services were the HACC program and CACP packages.

Before entry to DDR, Government programs and packages were more often used where the care recipient was *frail, unwell or terminally ill* compared with cases where the care recipient did not suffer from those conditions. However other health conditions including dementia status, and the demographic characteristics of carers and care recipients, did not significantly influence the use of programs/packages in this phase.

In cases where a package (CACP/EACH/EACHD) had been used prior to entering the DDR service, carers had mostly become aware of the DDR program either *through an assessment for a program/package* or through a *carer information, support and linkage service*. In contrast, the most common source of introduction to DDR for those who had only been using HACC/VHC programs, or who had not been using any programs/packages at all, was through *another service or health provider*.

In terms of the types of services used by carers and care recipients prior to their involvement with the DDR program, *home help, personal care services* and *property maintenance services* were the most commonly used during this phase. Regarding services relating to *respite for carers*, 23% of carers had used *in-home respite care*, 21% had used *activity groups*, 19% had used *a centre-based day care service*, 20% had used *residential respite care at a RACF* and 9% had used *overnight respite care at a RACF*, before becoming involved with the DDR service.

Many carers had used a combination of two or more of these respite services, however just under half of all carers in the sample *had not used any respite services* prior to their involvement with the DDR service.

Programs, packages and services used in conjunction with DDR

Overall, the use of *Government programs and packages* increased only slightly during carers' involvement with the DDR service, and the change was not statistically significant. However after entry to DDR, 29% of carers/recipients accessed additional *types of services* compared with their usage profile prior to DDR.

The services most commonly commenced by carers during their involvement with DDR were *residential respite care at a RACF* and *carer information, support and linkage services*. There was a statistically significant increase of 9% in the use of each of these types of service after entering DDR.

Almost two thirds of carers (65%) were using at least one *non-DDR respite service* in conjunction with the DDR service. This represented a significant increase compared with the pre-DDR phase of the pathway (55%).

Several factors may have contributed to the increased uptake of these services during involvement with DDR – information/recommendations provided to carers by the DDR service, carers' and care recipients' increased familiarity

with the residential care setting as a result of their involvement with DDR, and an increasing need for support as both the carer and care recipient age.

Exit pathways

Nearly a third of carers who responded to the survey had exited from the DDR service. In around half of those cases (52%), the care recipient had *entered full time residential care* by the time the survey was conducted. A further 23% of those who had exited the DDR service did so when the care recipient passed away. The remaining 25% of care recipients who were no longer attending the DDR service were still residing in the community after their exit.

Two thirds of the care recipients who had entered full time residential care had gone into *high level* residential care. Care recipients with *dementia* were significantly more likely to have transitioned to full time residential care (either high level or low level) than those without dementia.

In terms of the programs, packages and services used by carers and care recipients after exit from DDR, the high proportion of exits to full time residential care or death meant that there was a *net overall decrease* in usage during this phase.

For cases where the care recipient was still living in the community after exiting DDR, the services most commonly used were *home help, personal care services, property maintenance services and in home respite care*. In total more than half of these carers were using some type of *respite service* after exiting DDR. *Older carers* (aged 80+) were significantly more likely than younger carers to be using a respite service at this time.

Exit from DDR to the community did *not* result in significant take up of other respite services by these individuals, at least by the time the survey was conducted.

Entire pathways

An examination of the full range of different pathways taken by subgroups of carers revealed a *trend of continuity* in the programs, packages and respite services used across the first two phases (before DDR and during DDR) which was generally sustained post-exit for cases where the care recipient had continued to reside in the community.

For cases where the use of Government programs/packages had changed across the pathway, the direction of change was usually towards additional or more intensive types of program/package – from nil programs/packages to at least one type of program/package, or from using HACC/VHC programs in isolation towards using package(s) as well as, or instead of, HACC/VHC.

Similarly, where there had been changes in the use of respite services across the pathway these mainly involved engaging with a (non-DDR) respite service for the first time, using more resource-intensive types of respite such as *in home respite* and *residential respite*, or using a broader combination of respite types over time.

2 INTRODUCTION

2.1 CONTEXT FOR THE CLIENT PATHWAY ANALYSIS

2.1.1 THE DDR INITIATIVE

The *Demonstration Sites for Day Respite in Residential Aged Care Facilities* Initiative is funded by the National Respite for Carers Program (NRCP) and was announced as part of the 2007/2008 Federal Budget. The NRCP aims to contribute to the support and maintenance of caring relationships between carers and their dependent family members or friends by facilitating access to information, respite care and other support appropriate to their individual needs and circumstances, and those of the people for whom they care.

The objectives of the Initiative are to:

- ⇒ Provide new day respite options for carers of frail aged people;
- ⇒ Showcase innovative models of respite; and
- ⇒ Provide an opportunity to conduct research into the provision of day respite services in residential aged care facilities.

Under the Initiative \$41.2 million has been provided over four years to establish demonstration sites for day respite care in aged care facilities. Applications for funding to establish and operate a demonstration day respite service were sought from approved providers of residential aged care. Thirty providers from metropolitan and rural and remote areas across Australia were offered funding. These providers operate Demonstration Day Respite (DDR) services at a total of 31 sites across Australia.

2.1.2 EVALUATION OF THE DDR INITIATIVE

The Evaluation of the *Demonstration Sites for Day Respite in Residential Aged Care Facilities* Initiative investigated and reported on the following 9 factors:

1. The **efficiency, effectiveness and appropriateness** of funding DDR services in residential aged care facilities.
2. The **benefits** to the carer and care recipient of accessing DDR services in residential aged care facilities, including the extent to which this model of respite care supports home-based care, the caring relationship and the well-being of the carer and the care recipient.
3. Any **unintended effects** of the Initiative, including adverse consequences for the carer or care recipient.
4. The **impact** of accessing DDR services on the care recipient's entry to permanent residential care, including the extent to which the receipt of day respite delays or else facilitates entry into full-time residential care.
5. The effects of providing DDR services on the **operations** of residential aged care facilities in providing care to full time residents.
6. The **demand** for DDR services in residential aged care facilities.
7. The **costs** of delivering DDR services, taking into account relevant variables including: locality, level of care provided, needs of care recipients, facility size etc.
8. Appropriate levels of **user fees** for DDR services.
9. Appropriate **options for future funding** of this type of respite, such as a day respite subsidy and/or grant funding.

The Evaluation was undertaken by the Australian Institute for Social Research (AISR) at The University of Adelaide. The major components of this Evaluation were undertaken in 2009 and 2010, culminating in a Final Report submitted to the Department at the end of December 2010. The main Evaluation activities comprised the following –

- Discussion Paper presenting a review of Australian and international research;
- Development of a Monitoring and Evaluation Framework;
- Case Studies;
- Surveys of CEOs/Service Directors, Care Coordinators/Managers, Care Workers, and Carers;
- Collection of other data from sites (known as *Site Data*, two collections);
- Analyses of Service Activity Report (SAR) data; and
- Analyses of Financial Accountability Report (FAR) data.

2.1.3 DISTINGUISHING FEATURES OF THE DDR EVIDENT FROM THE EVALUATION

The provision of day respite services usually occurs in a community rather than a residential care setting, and this is the distinguishing feature of the DDR model – its location. From this base several other differentiating features were evident from the Evaluation of the DDR Initiative –

- Co-location of day respite in a RACF brings together residential and community care staff, offering scope for the development of enhanced knowledge and skills on the part of both groups of staff, and can provide the day respite service with access to staff they may not normally be expected to work with (e.g. Lifestyle Coordinators).
- Co-location also offers the opportunity for residential and DDR service recipients to share in activities, broadening the range otherwise possible. In smaller communities (e.g. rural or culturally specific) many of the residents are known to day respite users and given the opportunity to re-connect.
- Co-location brings the risk that the stigma associated with a residential care setting will deter carers and care recipients from accessing the DDR service. A critical factor in the application of the model is sensitive infrastructure design that provides a specific identity for the DDR service and supports flexible service provision.
- Co-location and the familiarisation involved also means that many carers and care recipients can more easily access residential respite, and that if the care recipients' needs change and they require long term residential care, this is less threatening.
- For all of the above reasons, the DDR model can be seen as building a bridge between community and residential care, providing an important linking component in the care continuum and easing the carer and care recipient journey in the process.

Clearly, the DDR model provides a range of potential additional benefits for carers and care recipients beyond what would be available under more traditional day respite arrangements.

2.1.4 THE NEED FOR A CLIENT PATHWAY ANALYSIS

During the course of the Evaluation the Department of Health and Ageing (DoHA) identified a desire for additional information regarding the broader journey of carers. In particular, the Department became interested in –

- What programs and services carers used prior to entering the day respite service;
- How carers became aware of the day respite service;
- How long carers had spent on a waiting list for the day respite service;
- What services carers used in combination with day respite;
- Carers' reasons for exiting the service;
- What services carers used after exiting the service;
- Whether there were different subgroups of carers who followed different service pathways; and
- Whether different pathways were associated with different carer/care recipient characteristics.

The Department therefore commissioned an analysis of client pathways into and out of DDR services. This has been undertaken as an additional step in the overall Evaluation.

Although a discrete component of the Evaluation, the Client Pathways Analysis also complements qualitative information about entry into and exit from the service already obtained through interviews with service managers, as well as survey-based feedback obtained from carers, care workers, care coordinators and service directors. In addition, the Evaluators' analysis of data collected directly from each site (Site Data) included detailed information on carers and care recipients entering and exiting the day respite service during a defined 6 month period as well as those who were existing clients during that timeframe.

2.2 RELEVANT FINDINGS FROM THE RESEARCH LITERATURE

There are few studies that involve the tracking of aged care clients or carers through the service system. However, the *Pathways in Aged Care (PIAC) Project* fills a critical gap and an overview of its findings follows.

2.2.1 THE PATHWAYS IN AGED CARE (PIAC) PROJECT

In 2006 a consortium of researchers at the Australian Institute of Health and Welfare (AIHW), University of Queensland and La Trobe University was successful in obtaining a National Health and Medical Research Council (NHMRC) grant to undertake analysis of care pathways in the aged care sector. The Pathways in Aged Care (or PIAC) project was a national cohort study which utilised data linkage to explore the care transitions and care pathways for older Australians.

The cohort for the PIAC project comprised 105,000 people who had a completed assessment by an Aged Care Assessment Team (ACAT) under the Aged Care Assessment Program (ACAP) recorded in 2003–04. Statistical data linkage was used to create a national database which combined data from ACAT assessments, death records and data on actual program use from 2002–03 to 2006–07 for five key aged care programs (AIHW 2009a, 2011: 3) –

- Home and Community Care (HACC)
- Community Aged Care Packages (CACPs)
- Extended Aged Care at Home (EACH) Packages including EACH Dementia (EACHD) Packages
- Permanent and Respite Residential Aged Care (RAC)
- Veterans Home Care (VHC).

This enabled investigation of movement between programs within the aged care system (AIHW 2011: 3).

2.2.2 KEY FINDINGS FROM THE PIAC RESEARCH

The main findings from the first report of the PIAC project relate to a cohort of 77,400 people who had an ACAT assessment in 2003–04 and who had not previously used aged care services requiring an ACAT assessment for access.

Patterns of service use were diverse, reflecting individual circumstances and need and therefore involving thousands of different pathways. The 77,400 people studied had 9,200 distinct pathways following their ACAT assessment, and where HACC or VHC programs were used prior to the assessment, the number of pathways increased to 10,743.

In order to overcome the difficulty in identifying common patterns in so many pathways, the AIHW considered the *order* in which people accessed or re-accessed care programs. The analysis excluded within-program transfers. Establishing these boundaries identified 2,030 different program use pathways, including those ending in death, over the 2 years following the ACAT assessment (AIHW 2009b: 10–11).

Despite the diversity of pathways, a relatively small set was used by a large proportion of the cohort – involving 14 pathways used by 82% of cohort members.

These 14 key pathways are summarised in Table 1 below. Each pathway begins with an ACAT assessment and then up to 3 changes were tracked over the ensuing 2 years. It is important to note that *change* in the use of care programs was the focus of the analysis, and therefore program engagement continuing across the point of the ACAT assessment is not illustrated in the table.

Table 1: Description of the 14 key pathways identified by the PIAC project

Path No.	1 st change	2 nd change	3 rd change	% with HACC or VHC before	% with no previous care	% of Total	Total No.
1	None following ACAT assessment			14.0	18.6	16.0	12,380
2	Permanent Residential Aged Care (RAC)			13.9	11.3	12.8	9,865
3	HACC/VHC			8.9	14.8	11.5	8,893
4	Perm RAC	Death		10.4	7.4	9.1	7,028
5	Death			9.6	6.0	8.0	6,190
6	Respite RAC	Permanent RAC		7.3	3.7	5.7	4,396
7	CACP			3.6	2.3	3.0	2,313
8	HACC/VHC	Death		1.8	4.2	2.0	2,228
9	HACC/VHC	Permanent RAC		1.9	4.0	2.8	2,196
10	Respite Residential Aged Care			3.4	1.6	2.6	2,002
11	Respite RAC	Perm RAC	Death	3.2	1.5	2.5	1,012
12	HACC/VHC	Respite RAC	Perm RAC	1.6	3.6	2.5	1,911
13	HACC/VHC	Perm RAC	Death	0.9	2.1	1.4	1,080
14	CACP	HACC/VHC		1.8	0.6	1.3	1,013
	<i>All other paths</i>			17.8	18.3	18.0	13,941
	Total			100.0	100.0	100.0	77,348

Source: AIHW (2009) *Pathways through aged care services: a first look*, Table 5, pg 13, Bulletin 73, Australian Institute of Health and Welfare, Canberra

Key findings from the PIAC research were –

- ACAT assessment does not necessarily lead to the use of additional aged care services – 24% of the PIAC cohort had not *newly* accessed any care programs within the first 2 years of their assessment, however one third of those people had died.
- For some, ACAT assessment appears to have provided information about community care programs that do not require this assessment – 21% accessed or re-accessed HACC or VHC programs as their first post-assessment step in the care pathway.

- The most common pathway (Path 1 in the table above) was the 'no change' path. In the two years after ACAT assessment, 16% of the cohort were still alive and had not *newly* accessed any care programs since their assessment. Around half of these people had previously accessed, or continued to access, HACC or VHC services.
- A further 22% of the cohort and of whom around 40% subsequently died, had used only permanent residential aged care in the two years after their ACAT assessment (Paths 2 and 4).
- A total of 14% of the cohort had accessed only HACC or VHC services in the two years after their ACAT assessment (Paths 3 and 8).
- Highlighting the importance of community aged care in pathways, the use of HACC or VHC services was the first step in five of the 14 most common pathways. These five paths were used by over one-quarter (29%) of the cohort with no previous care (AIHW 2011: 20).

2.2.3 FINDINGS RELATING TO RESIDENTIAL RESPITE CARE

Residential respite services were featured in four of the top 14 pathways representing 13% of the cohort. These pathways were –

- *Pathway 6:* Residential respite ⇒ Permanent residential care (5.7% of the cohort)
- *Pathway 10:* Residential respite only (2.6%)
- *Pathway 11:* Residential respite ⇒ Permanent residential care ⇒ Death (2.5% of the cohort)
- *Pathway 12:* HACC/VHC services ⇒ Residential respite ⇒ Permanent residential care (2.5% of the cohort).

These pathways demonstrate that use of residential respite care is often followed at a later date by admission into permanent residential care (AIHW 2009b: 13).

Residential respite pathways were more common among those who had accessed HACC or VHC services prior to their ACAT assessment (16%) compared with those who had not (10%).

Although residential respite featured in a number of common pathways, it was also apparent that at any one time, few people were using residential respite – reflecting its time limited nature (AIHW 2009b: 17).

Other findings were –

- Those who had not previously used HACC or VHC services tend to be younger, to have fewer health conditions and to have slightly fewer limitations in activities of daily living. They were also less likely to be admitted to permanent residential aged care.
- The use of care programs by individuals tended to increase over time, with a noticeable move towards residential care. For the cohort studied, 22% of those who were still alive 6 months after their ACAT assessment were in permanent residential aged care, and this proportion increased to 28% at 24 months after ACAT assessment.

Earlier research by the AIHW (based on the period 1/7/2002-31/3/2003) examined relationships between residential respite care, HACC, CACPs and permanent residential aged care. Analysis found that people accessed care from a number of sources at any one time and that movement between care programs is not necessarily in one direction only. Key findings included the following –

- Many people accessed residential respite care while receiving services through the HACC and CACP programs. Around one half of respite clients had used these programs before their period of respite care, but these programs were not the only route to respite care.

- A small number of people began using community care programs following a period of residential respite care. However in general, people tended to access residential respite care via community care rather than the other way round (AIHW 2006: 10).
- About one quarter of people who had recently used residential respite care were admitted to permanent residential care, and over half of this group had also used HACC or CACP services.
- 40% of people who exited residential respite care in one quarter had entered permanent residential care by the end of the following quarter.
- Among users of residential respite care, concomitant use of community care services appeared to delay entry into permanent residential care. About 46% of residential respite clients *not* using HACC or CACP services in one quarter were admitted to residential care by the end of the following quarter, compared with 35% of those who had accessed these community care programs (AIHW 2006: 1).

2.2.4 FINDINGS RELATING TO RESIDENTIAL RESPITE AND DEMENTIA

In a specific PIAC study of the service pathways of carers of people with dementia (AIHW 2010: 3), data were analysed for 32,000 people who had been approved for residential respite care by an ACAT assessment in 2003-04. Key findings were –

- A greater proportion of people with dementia accessed residential respite services (32%) compared with those without dementia (25%) (AIHW 2010: 7).
- Of those *recommended to live in the community*, people with dementia (31%) were more likely than those without dementia (26%) to use residential respite care within the first 12 months of their ACAT approval (AIHW 2010: 8).
- Of those *recommended to live in residential care*, people with dementia were somewhat more likely than those without dementia to use residential respite care within 12 months of their ACAT approval, but this effect was not as strong as that for people recommended to live in the community (AIHW 2010: 8).
- Not surprisingly, having a carer increased the likelihood of accessing residential respite care (34% of those with a carer versus 21% of those without a carer). This occurred for those recommended to live in the community or in residential care (AIHW 2010: 9).
- People with a co-resident carer (31%) were more likely to use residential respite care than those with a non-resident carer (25%) (AIHW 2010: 9).
- There was no interaction between dementia status and carer status in terms of the probability of taking up residential respite care (AIHW 2010: 9).
- For those recommended to live in the community, people born in NESB countries had a significantly lower take up rate of residential respite care (24%) than those born in Australia or other ESB countries (28%) (AIHW 2010: 10).
- There was no interaction between dementia status and English proficiency in terms of the probability of taking up residential respite care (AIHW 2010: 11).

The AIHW also found that the following factors were associated with take up of residential respite care, regardless of whether the person was recommended to live long term in the community or in residential care –

- Having care needs for activities of daily living.
- Particular health conditions, e.g. a disease of the musculoskeletal system.
- Locality of residence, e.g. people living in NSW were more likely to access residential respite services than those living elsewhere in Australia (AIHW 2010: 11).
- For those living long term in the community, previous use of government services was associated with an increased likelihood of accessing residential respite care, but was not significant for those recommended to enter residential care (AIHW 2010: 11).

3 METHOD

3.1 DESIGN OF METHODOLOGY

In determining the methodology for the Client Pathways Analysis we first explored the possibility of obtaining an extract of NRCP data for DDR carers and care recipients only, and were advised by DoHA that due to linking issues this could not be achieved. We also investigated the possibility of using administrative byproduct data from participating DDR sites as a data source, but found that none collected all of the information that we would require.

In the absence of suitable administrative byproduct data, and considering the Department's interest in information beyond that collected through administrative means, we concluded that the most comprehensive, practical and efficient alternative for collecting information on client pathways would be *directly from carers themselves*. Carers are the only potential source of *complete* data regarding their service use over time.

To this end, we developed a questionnaire (*Client Pathway Survey*) to collect information directly from carers regarding the programs and types of services they had used, and recruited a sample of sites to undertake this collection.

3.2 QUESTIONNAIRE DESIGN

The Client Pathway Survey tool was designed to be as simple and easy to fill out as possible. The questionnaire was structured so as to limit the cognitive burden on carers by –

- a) allowing them to choose from *lists* of programs and services that they might have used/be using, rather than being required to recall these without prompting,
- b) providing space for them to indicate any other programs and services that they recalled using after being prompted by the list, and
- c) focusing on three well-defined periods – *before, during* and *after* their involvement with the DDR service.

Therefore by relying more on recognition than free recall, the questionnaire design supported carers' ability to provide as full and accurate a picture as possible regarding their service use over time.

The questionnaire also provided carers with an opportunity to consider, in hindsight, what extra services they may have found helpful at different stages of their journey.

In order to define a manageable population for site-based survey distribution, the survey was intended for carers who had used a DDR service *at some time in 2010*, whether or not they were currently still in the Program. We took care when designing the questionnaire to ensure that carers of care recipients who were now deceased were treated in a sensitive manner.

The questionnaire also contained many of the demographic and health-related questions included in the 2009 Survey of Carers, so that the representativeness of the sample could be assessed against other data from the Evaluation (survey, site data, SARs). Other important aspects of the sample, such as carers' duration of involvement with the DDR service and their reasons for exit from the service, were also collected for comparison against this other information.

A copy of the survey tool appears in *Section 6*.

3.3 RECRUITMENT OF SITES

All 31 DDR sites were invited via email to take part in the Client Pathway Survey as an *optional* component of the Evaluation. Our aim was to recruit at least *nine* sites covering diverse demographic and service features and which were motivated to undertake the survey distribution required.

As a result of the email invitation ten sites volunteered to take part in the survey. Sites which did not respond to the invitation but which were of special interest to the Evaluators in terms of achieving a representative sample (e.g. Rocky Ridge's Indigenous specific service) were then followed up by telephone to determine whether they would be willing to take part.

At the end of the site recruitment process, a total of *fourteen* sites representing diverse client and carer groups, locations and service features agreed to take part in the Survey. These sites, and their key distinguishing features, are listed in Table 2.

Table 2: Day Respite Services which participated in the Client Pathway Survey

Name of Day Respite Service	Provider of the service	Distinguishing features
NSW		
Warnervale Wellness Centre's Day Respite Service	Catholic HealthCare, Central Coast	Healthy ageing focus. Regional location.
Constitution Hill Day Respite Centre	Australian Unity Retirement Living Services. Western Sydney	Co-located with Constitution Hill Retirement Village Community, and all its services.
Our Lady of Consolation Day Respite Service	Our Lady of Consolation Aged Care, Rooty Hill	Outer metropolitan. Healthy ageing & health promotion focus.
Warrigal Community Care Day Respite Service	Warrigal Care, Goulburn	Regional location.
VIC		
The Caring Café	Inner East Community Health Service, Melbourne	Community health – seamless link to RACF & primary health services.
Homestead Day Stay Respite	Lyndoch Warrnambool Inc, Warrnambool	Regional location.
Manningham Centre Day Guest Respite Service	Manningham Centre Assoc Inc, Doncaster, Melbourne	Metropolitan location.
QLD		
Garden City Retirement Home's Day Respite Service	Alzheimer's Assoc of Qld Inc, Brisbane	Dementia-specific.
Spiritus Wide Bay (Kirami) Day Respite Service	Spiritus Care Services, Bundaberg and Point Vernon	Regional location.
SA		
Perry Park's Riverview Day Respite Service	ACH Group Inc, Port Noarlunga	Outer metropolitan. Strong focus on carer and client centred care.
Ross Robertson Day Respite Service	ECH Inc, Victor Harbor	Regional centre, 2 nd highest concentration of older people outside of Adelaide.
WA		
St Ives Day Respite Service	Aged Care Services Australia Inc, St Ives Group, Myaree, Perth	Metropolitan.
Morrison Lodge Day Respite Service	City of Swan Aged Persons Trust Inc, Midland, Perth	Outer metropolitan.
NT		
Rocky Ridge Day Respite Service	Uniting Church Frontier Services, Katherine	Indigenous specific. Remote location. Also auspice for Commonwealth Carelink and the Carer Respite Centre.

3.4 SURVEY IMPLEMENTATION AND MONITORING

The survey implementation strategy reflected that developed previously for the Evaluation's Survey of Carers (2009), as feedback had indicated that this process was not unduly burdensome for sites or carers.

The only modification to the original implementation strategy was the introduction of additional guidelines for the verbal administration of questionnaires at the Rocky Ridge site. The verbal administration approach was *first* introduced for the 2009 Survey of Carers, in response to the Site Coordinator's recommendation that this would be the most culturally appropriate and user appropriate means of obtaining information, even though it posed an additional burden on staff at the site. However the suggested approach met with limited success for the 2009 Survey of Carers – only three survey forms were completed at the Rocky Ridge site. Further consultation with the Site Coordinator leading up to the Client Pathway Survey indicated that a goal of ten completed questionnaires was reasonable, of which seven were actually attained.

Prior to the launch of the Client Pathway Survey, each site provided information to the Evaluators regarding the number of questionnaires they would require and the contact details of the person who would be responsible for distribution. The questionnaires were then printed by a professional printing service. Each questionnaire and accompanying reply paid envelope was packaged within a plain unsealed A5 envelope, for easy handout or mailout to individual carers.

The specified number of questionnaire packages was dispatched to each participating site at the end of January 2011. A covering letter provided guidelines for distribution. The letter also included a tear-off portion for the distributor to complete and return, reporting the date on which distribution had been completed and the number of questionnaires that had actually been distributed (required for response rates).

The letter asked the sites to distribute the questionnaire packages to carers who had used the DDR service *at some time in 2010*, including those who had since exited the service. We believed that these carers would be easy for the sites to identify and would be receptive to receiving a questionnaire.

It was up to each individual site to determine how best to undertake their local distribution. We suggested hand-delivering the questionnaire to carers with whom they had regular contact, and mailing the remainder to carers who had irregular contact with the service or who had exited the service. We recommended that sites insert a "with compliments" slip or a simple introductory letter into each questionnaire package, particularly for those they mailed out.

Most of the sites were able to distribute the questionnaires by the end of February 2011. The Rocky Ridge site experienced delays due to staff shortages and undertook their data collection in March 2011. Undertaking the survey at Rocky Ridge required significantly more staff resources than at other sites due to the need to administer most of questionnaires verbally, due to language and literacy barriers.

The Evaluators monitored the flow of returns and followed up sites where delays were apparent. Delays in survey receipt and return were particularly evident for Queensland respondents, due to the floods across this region in early 2011. A significant number of returns from Queensland, NSW and NT continued to arrive throughout April 2011, therefore the closing date for the survey was extended to the end of April 2011.

3.5 DATA CAPTURE AND STORAGE

Questionnaire responses were entered into a system specifically prepared to capture this data. Staff were trained to undertake the data entry, and data quality aspects were monitored regularly.

After data entry and data cleaning was complete, the hardcopy survey forms were bundled and stored in AISR's secure storage area. All electronic data files were stored on a secure network which was only accessible to AISR staff involved in the project.

3.6 DATA ANALYSIS

Data were cleaned, coded and analysed using PASW Statistics V18.0. The cleaning phase included checking for data entry errors, checking internal consistency, and managing missing data.

The coding phase included categorising the qualitative information from text fields, and coding the information from demographic items to the ABS standard classifications for each of those items. The ABS classifications used were –

- Standard Australian Classification of Countries (SACC), Second Edition, 2008, ABS Cat. No. 1269.0
- Australian Standard Classification of Languages (ASCL), 2005-06, ABS Cat. No. 1267.0
- Australian Standard Geographical Classification (ASGC), ABS Cat. No. 1216.0
- ASGC Remoteness Structure (RA) Digital Boundaries, ABS Cat. No. 1259.0.30.004.

Analysis of the data was undertaken using a range of data manipulation techniques as well as inferential statistics to assess relationships between variables, differences between subgroups, and changes over time. Both parametric and non parametric techniques were used according to the properties of the data being compared. Holm's sequential Bonferroni method (Holm, 1979) was used to assess the significance of results from sets of post-hoc pairwise comparisons.

Graphical presentation of results was undertaken using Microsoft Excel.

4 FINDINGS

4.1 THE SAMPLE

A total of **232** carers across fourteen sites responded to the survey. The overall response rate was **42.0%**, which is good for this type of survey. This reflects both the distribution efforts of the day respite coordinators and the willingness of carers to participate in aspects of the evaluation of the DDR program.

This section describes the sample in terms of –

- participation,
- location,
- demographic characteristics,
- health and wellbeing,
- duration of involvement with the DDR service, and
- the characteristics of respondents who had exited the DDR service.

It also compares the features of this sample against other sources from the evaluation.

4.1.1 PARTICIPATION BY SITE

4.1.1.1 NUMBER OF RESPONDENTS

The distribution of survey respondents across the fourteen participating sites was mostly related to the size of the client base at each site. Naturally, larger sites such as Constitution Hill (NSW), Our Lady of Consolation (NSW), Warrigal Care (NSW) and Morrison Lodge (WA) were more prominent in the sample – see Table 3.

Table 3: Number of respondents from each participating Site

State	Residential Aged Care Facility	No. responses	% of Total
NSW	Warnervale Wellness Centre's Day Respite Service (Catholic HealthCare)	18	7.8%
NSW	Constitution Hill Day Respite Centre (Australian Unity Retirement Living Services)	21	9.1%
NSW	Our Lady of Consolation Day Respite Service (Our Lady of Consolation Aged Care)	19	8.2%
NSW	Warrigal Community Care Day Respite Service (Warrigal Care)	24	10.3%
VIC	The Caring Café (Inner East Community Health Service)	14	6.0%
VIC	Homestead Day Stay Respite (Lyndoch Warrnambool Inc)	17	7.3%
VIC	Manningham Centre Day Guest Respite Service (Manningham Centre Assoc Inc)	17	7.3%
QLD	Garden City Retirement Home's Day Respite Service (Alzheimer's Assoc of Qld Inc)	16	6.9%
QLD	Spiritus Wide Bay (Kirami) Day Respite Service (Spiritus Care Services)	6	2.6%
SA	Perry Park's Riverview Day Respite Service (ACH Group Inc)	16	6.9%
SA	Ross Robertson Day Respite Service (ECH Inc)	19	8.2%
WA	St Ives Day Respite Service (Aged Care Services Australia Inc, St Ives Group)	10	4.3%
WA	Morrison Lodge Day Respite Service (City of Swan Aged Persons Trust Inc)	28	12.1%
NT	Rocky Ridge Day Respite Service (Uniting Church Frontier Services)	7	3.0%
TOTAL		232	100.0%

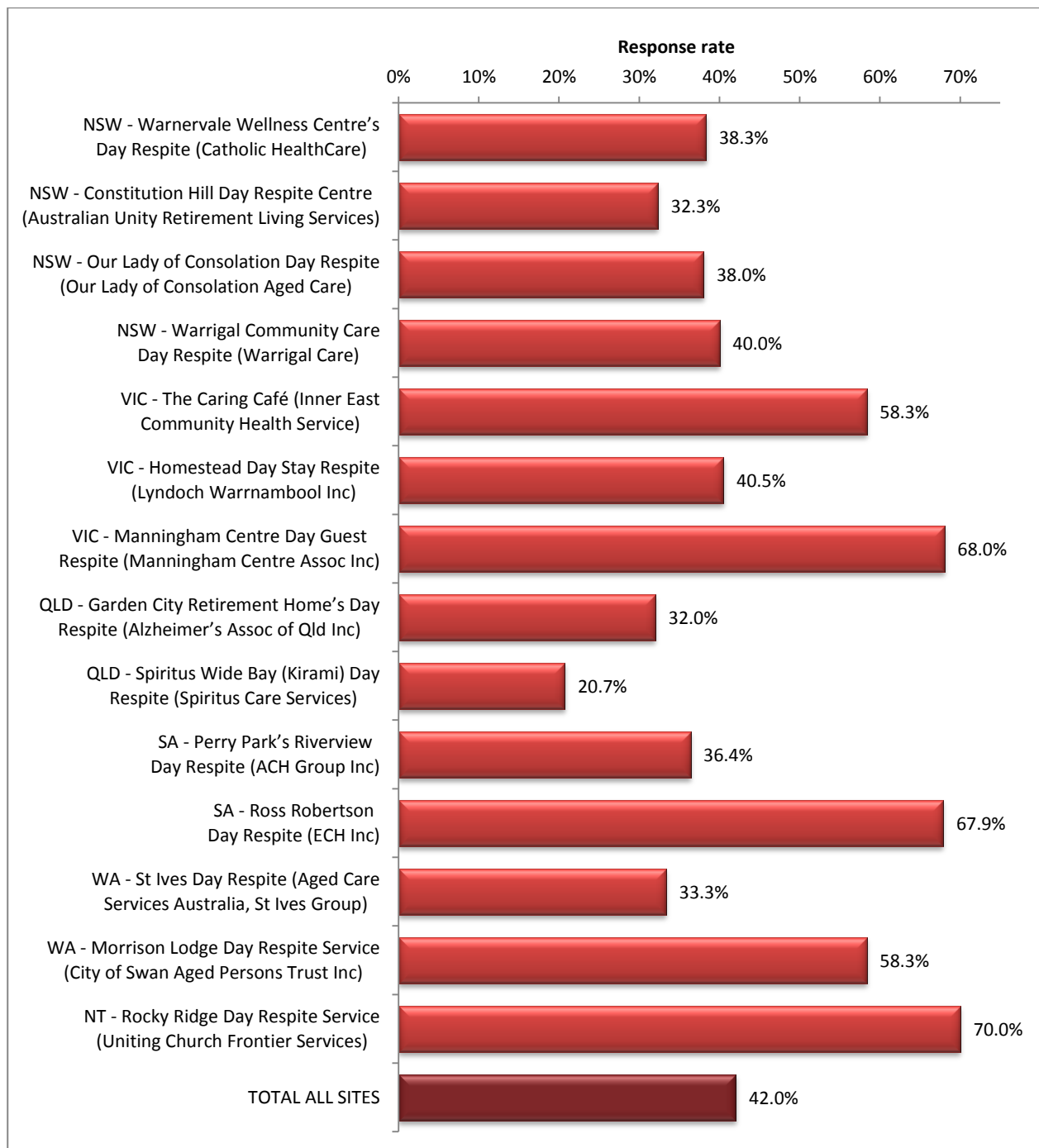
4.1.1.2 RESPONSE RATES

While the overall response rate was good at 42.0%, there was substantial variability in response rates across the fourteen sites. Response rates at individual sites ranged from 20.7% through to 70.0%.

As shown in Figure 1, the two Queensland sites, one metropolitan NSW site (Constitution Hill) and one metropolitan WA site (St Ives) recorded the *lowest response rates* at 33.3% or less. The lower response rates in Queensland were at least partly due to the widespread natural disaster (flooding) that occurred across that State during the survey period.

The *highest response rates* (greater than 67%) were recorded for one of the Melbourne sites (Manningham Centre), the regional SA site (Ross Robertson) and the remote NT site (Rocky Ridge). The high response rate recorded for Rocky Ridge was due primarily to the use of an interview-based survey delivery method for selected clients.

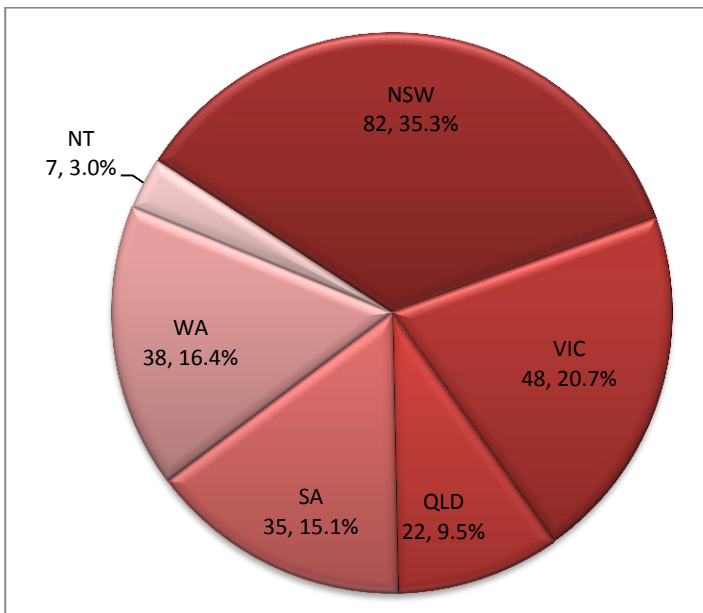
Figure 1: Response rates by Site



4.1.2 LOCATION OF RESPONDENTS

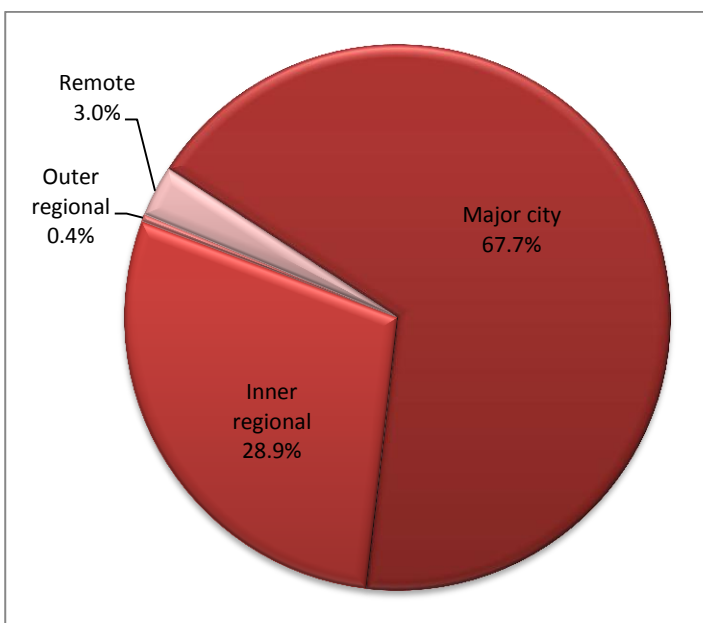
The distribution of respondents across States and regions was a consequence of the particular sites which participated in the survey. Just over half (56.0%) of the 232 respondents were from NSW or Victoria, and a further third (31.5%) were from SA or WA. Just under 10% were from Queensland, due to the relatively small sites involved and also due to lower response rates from this State. Three percent of the total sample comprised carers from the NT's Rocky Ridge site.

Figure 2: State distribution of respondents



Two thirds (67.7%) of carers who responded to the survey resided in a major city, and a further 28.9% lived in an inner regional area – see Figure 3. Only three percent of respondents, i.e. those using the Rocky Ridge service in Katherine NT, resided in a remote area, and one respondent (0.4%) indicated that they resided in an outer regional area, some distance away from the person for whom they were caring.

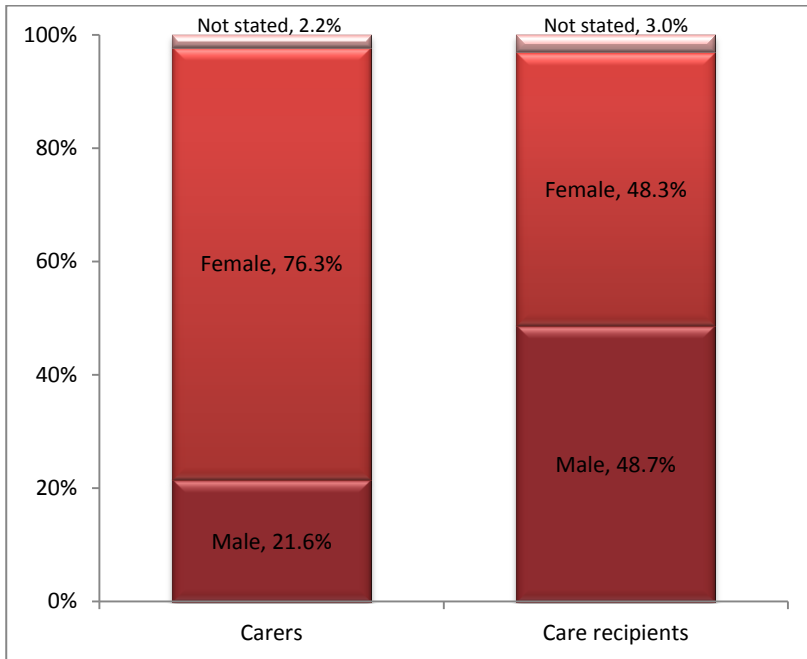
Figure 3: Remoteness area distribution of respondents



4.1.3 DEMOGRAPHIC CHARACTERISTICS OF CARERS AND CARE RECIPIENTS

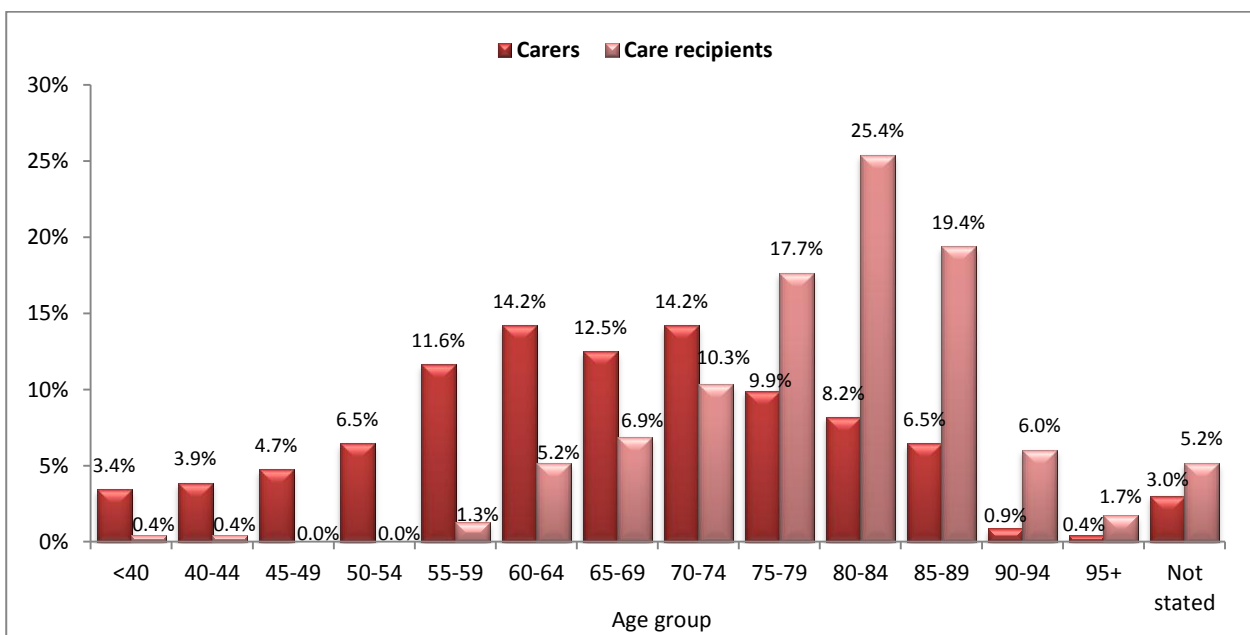
As expected, the majority of carers responding to the survey were female (76.3%) whereas the gender split for care recipients was approximately equal – see Figure 4.

Figure 4: Sex of carers and care recipients



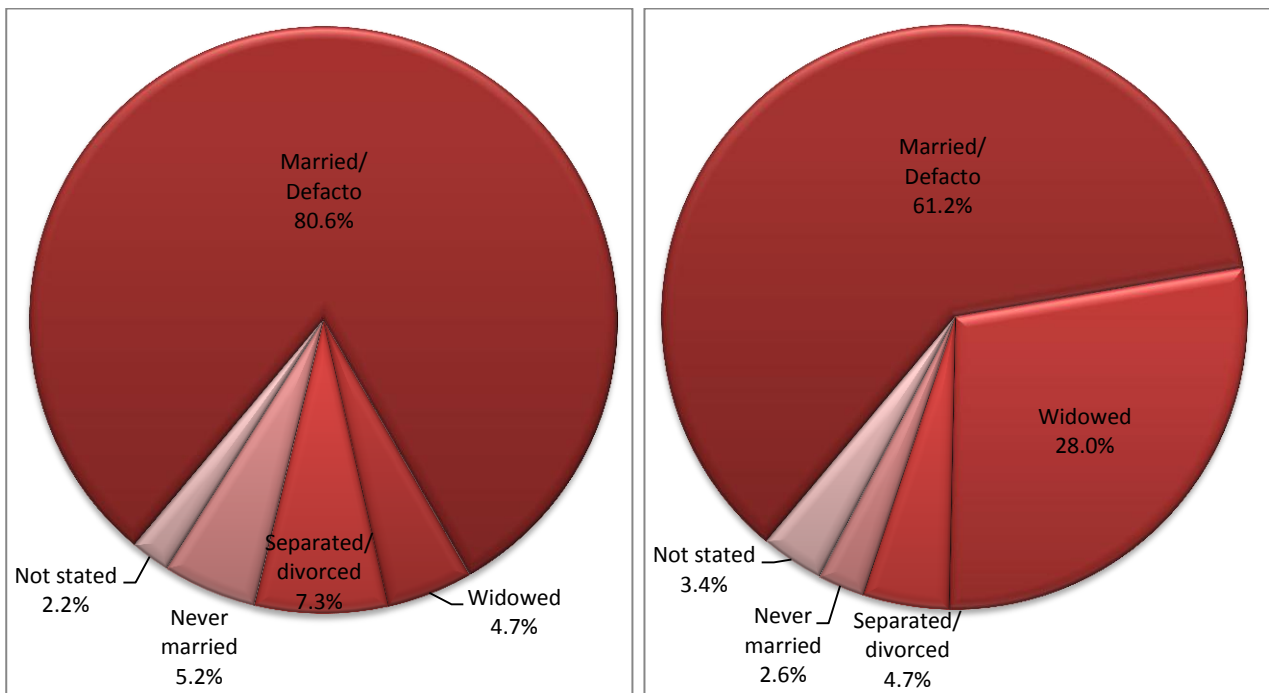
The age profile of the carers and care recipients in our sample reflects the usual finding that carers of people with age-related difficulties are generally younger than the people they care for – see Figure 5. Over half of all care recipients were at least 80 years old, whereas the majority of carers were under 70 years of age.

Figure 5: Age profile of carers and care recipients



The marital status profile of the carers and care recipients was in keeping with their age profiles, with over a quarter (28.0%) of care recipients being widowed, compared with only 4.7% of carers – see Figure 6.

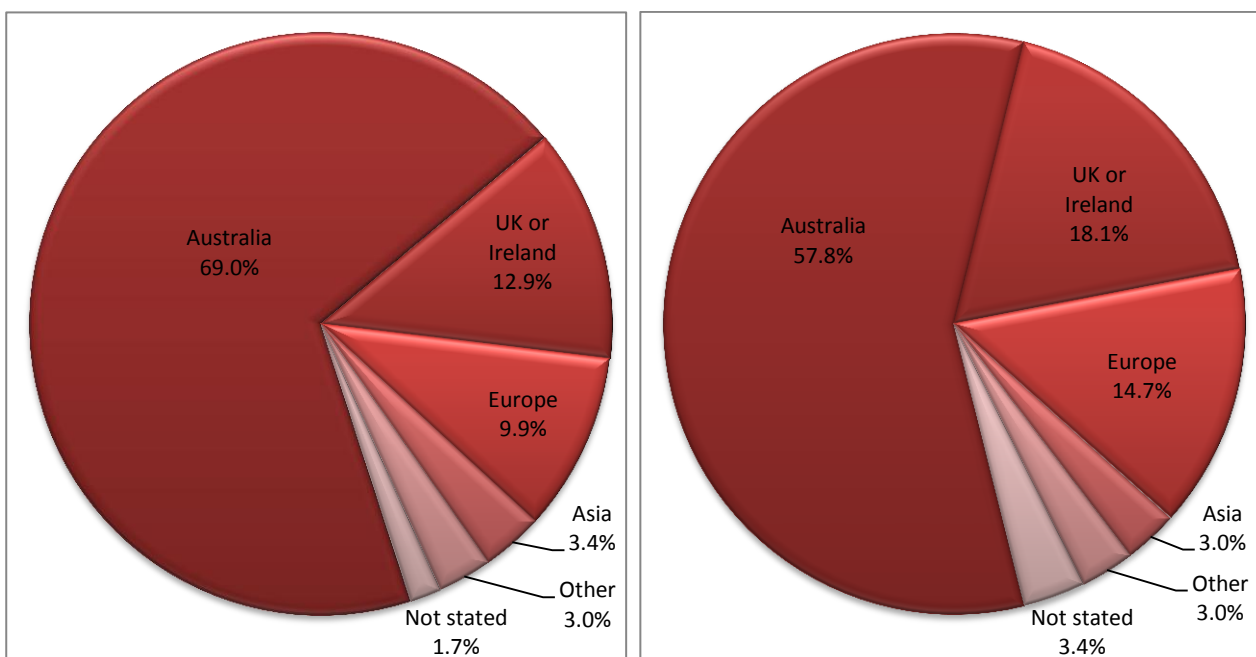
Figure 6: Marital status of carers (left) and care recipients (right)



Six carers and care recipients (2.6% of the sample) identified as being of Aboriginal or Torres Strait Islander origin, although note that around 5% of carers chose not to answer this question.

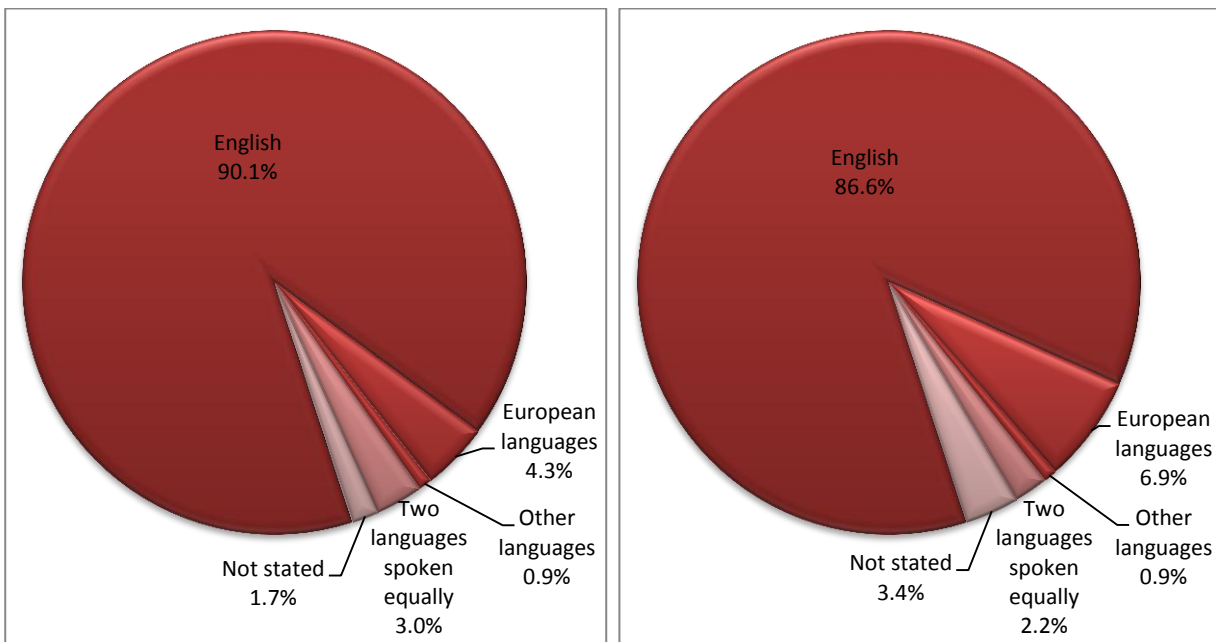
The majority of carers (69.0%) and care recipients (57.8%) had been born in Australia, with the remainder split mainly across the United Kingdom, other European countries, and Asia – see Figure 7. Nineteen percent of care recipients and 14.7% of carers had been born in a non English speaking country.

Figure 7: Country of birth of carers (left) and care recipients (right)



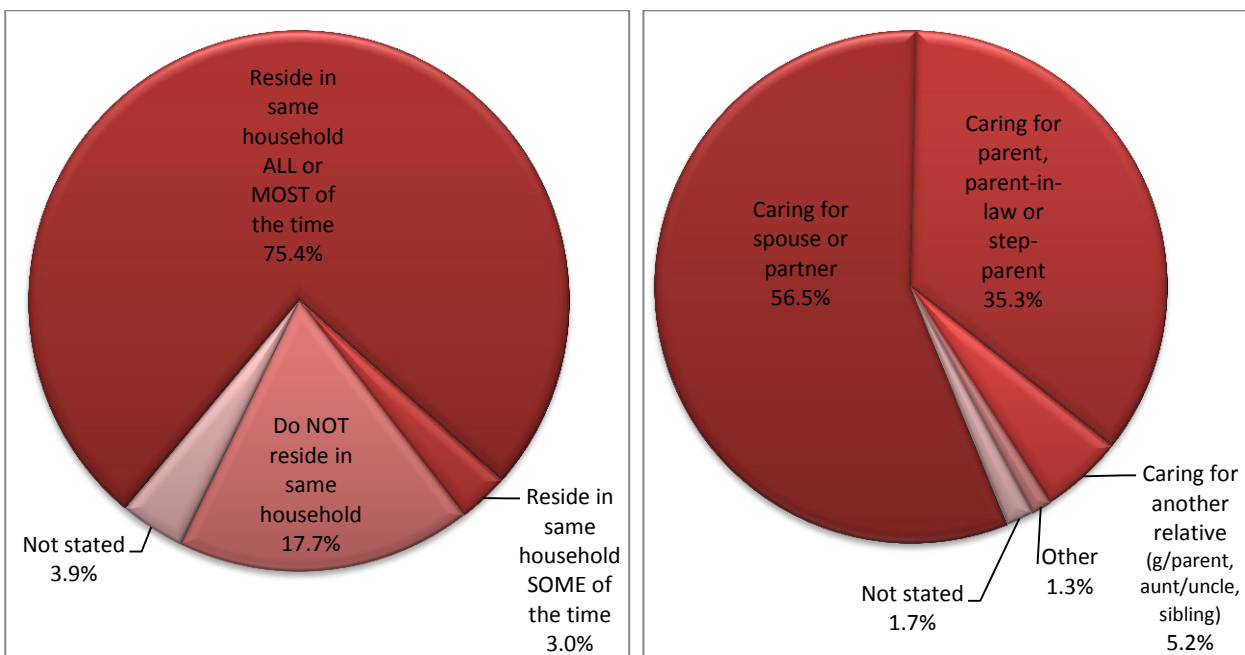
English was the main language spoken at home for 90.1% of carers and 86.6% of care recipients. European languages such as Greek and Italian were the primary language of 4.3% of carers and 6.9% of care recipients, while some respondents indicated that they spoke English and another language to an equal extent. See Figure 8 for details.

Figure 8: Main language spoken at home by carers (left) and care recipients (right)



Three quarters of carers resided in the same household as the person they cared for, over half of all carers were caring for their spouse or partner and around a third were caring for their parent, step-parent or parent-in-law – see Figure 9.

Figure 9: Living arrangements (left) and relationship (right) of carer and care recipient

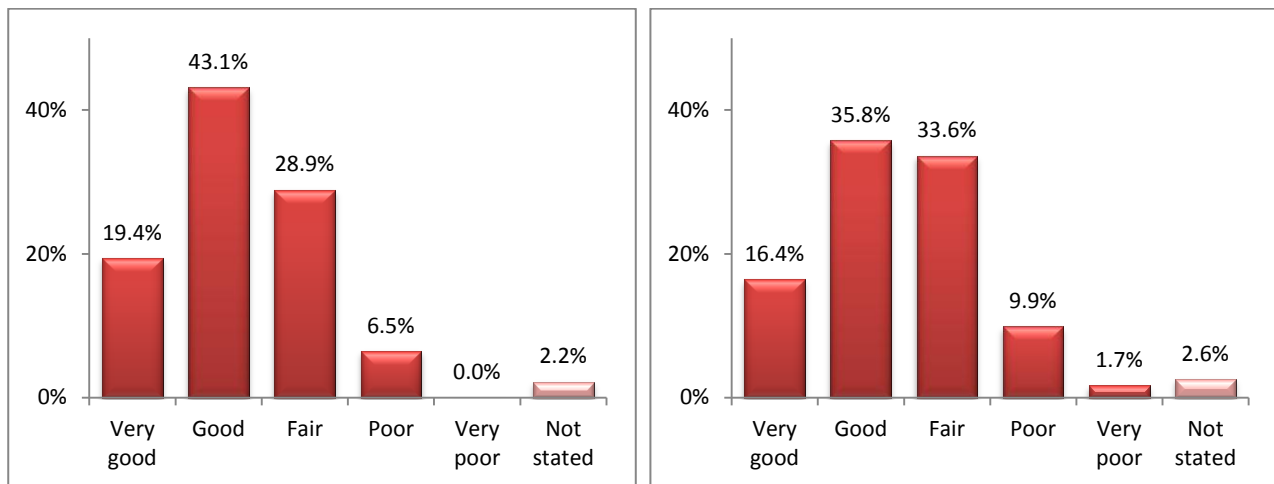


As would be expected, almost all of those caring for their spouse or partner resided with that person, while only 54.9% of those caring for their parent, step-parent or parent-in-law did so. Even fewer of those caring for another relative, friend or neighbor were co-residents (33.3%).

4.1.4 HEALTH AND WELLBEING OF CARERS AND CARE RECIPIENTS

Over 60% of carers described their present physical health as good or very good, however emotional health and wellbeing was not rated quite as positively – see Figure 10. More than 10% of carers rated their present mental health as poor or very poor.

Figure 10: Carers’ description of their current physical health (left) and emotional and mental well being (right)



Self-reported physical and mental health were highly correlated ($r=.63, p<.001$). For example, less than half (45.7%) of carers responding to the survey indicated that both their physical *and* mental health was good or very good.

Carers reported that the main health conditions or difficulties experienced by the care recipient while involved with the DDR service were *Dementia/memory loss issues* (68.5%) and *Frailty/poor mobility* (44.8%) – see Table 4. More than one health condition/difficulty was reported for almost half (48.3%) of the care recipients.

Table 4: Health conditions and difficulties reported for care recipients

Health condition or difficulty	No. of responses	% of respondents ¹
Dementia/memory loss issues	159	68.5%
Frailty, mobility problems	104	44.8%
Psychological problems (e.g. depression, severe anxiety)	40	17.2%
Unwell/in poor health	39	16.8%
Behaviours that are difficult to manage	30	12.9%
Terminal illness (e.g. due to cancer)	12	5.2%
Other	31	13.4%
Not stated	6	2.6%

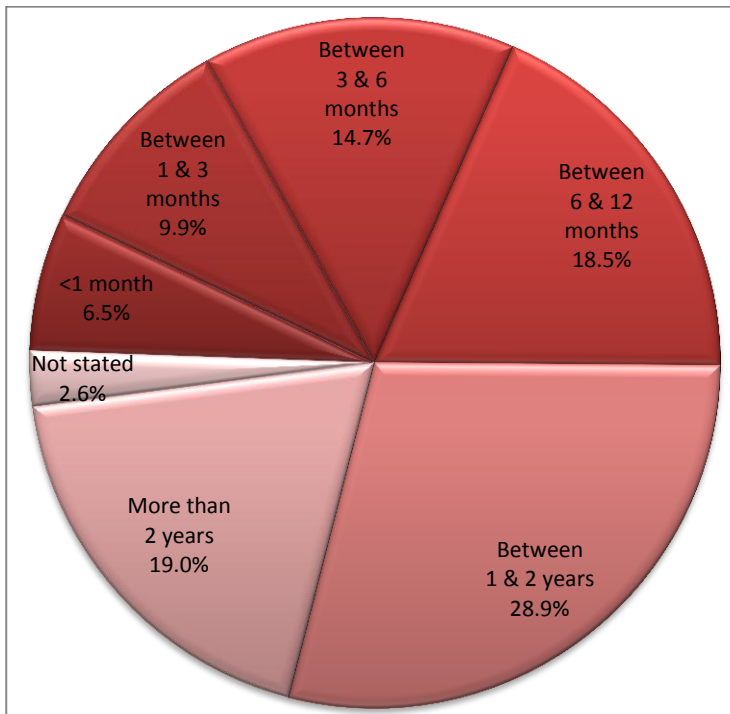
¹ Respondents could specify more than one condition or difficulty, therefore the total does not add to 100%.

The most common *other conditions* cited were neurological conditions such as Parkinson’s disease, Huntington’s disease, supranuclear palsy, multiple sclerosis and post-stroke neurological deficits. These were reported for 9.5% of care recipients.

4.1.5 DURATION OF INVOLVEMENT WITH THE DDR SERVICE

Two thirds of carers who responded to the survey had been using the DDR service for *at least six months*, however the survey also captured a good proportion of carers who were quite new to the service (up to 3 months, 16.4%) – see Figure 11.

Figure 11: Duration of involvement with the DDR service

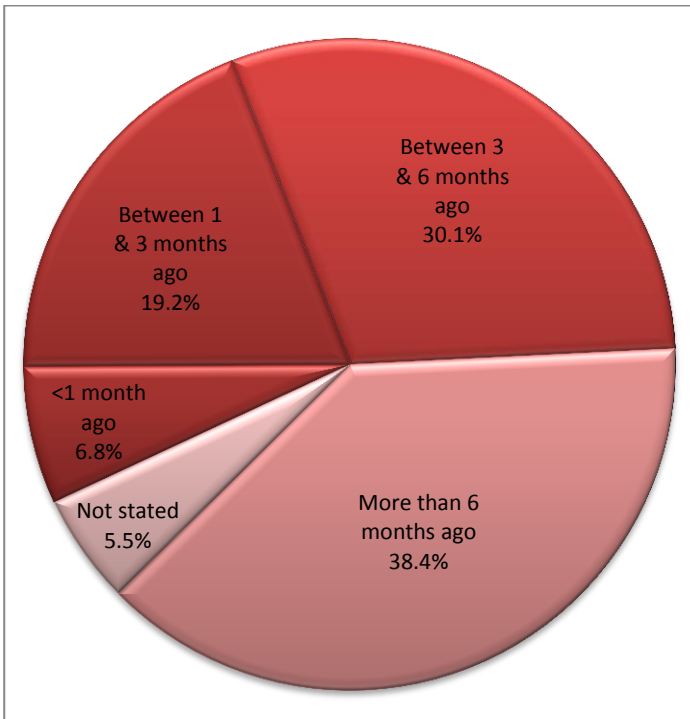


4.1.6 CHARACTERISTICS OF RESPONDENTS WHO HAD EXITED THE DDR SERVICE

Nearly a third (31.5%) of those who responded to the survey had exited from the DDR service.

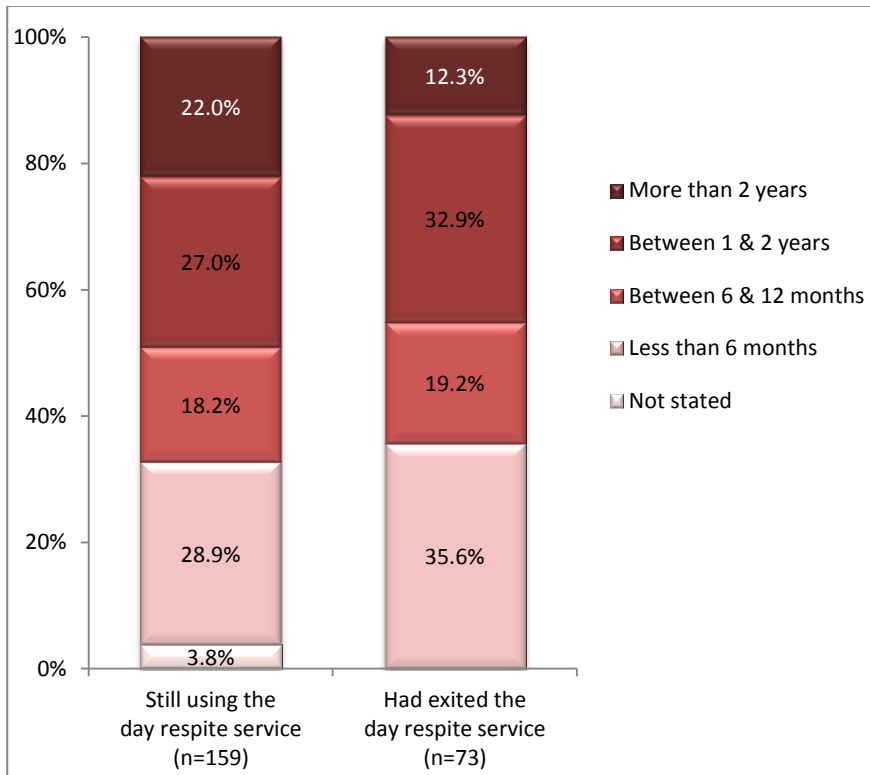
Of the 73 respondents who had exited the DDR service, the majority (68.5%) had ceased using the DDR service at least 3 months prior to participating in the survey. However respondents who had exited the service quite recently (1 to 3 months prior) or very recently (less than 1 month prior) were also well represented – see Figure 12.

Figure 12: Time since exit from the DDR service



As would be expected, respondents who had exited the service had generally had spent less time with the service than those who were still using the service – see Figure 13.

Figure 13: Duration of involvement with the DDR service, by exit status



There were no statistically significant differences found between those who had exited the DDR service and those who were still using the DDR service on any demographic and health characteristics, including dementia status.

4.1.7 COMPARISON OF THE SAMPLE AGAINST OTHER SOURCES FROM THE EVALUATION

Demographic, health and service usage characteristics of the Client Pathway Survey sample were compared against other data sources from the DDR evaluation, as follows –

- the Survey of Carers (2009)
- the detailed Site Data Collection (Round 1), covering June to December 2009
- 2009/10 data from Service Activity Reports (SARs).

The results are shown in Table 5 (demographics) and Table 6 (health and service usage). Overall the results demonstrate that the samples achieved for each survey were representative of the broader population of carers and care recipients, and in fact many results were very stable across disparate sources. Moreover, the characteristics of each survey sample were remarkably consistent with each other, even though the sample for the Client Pathway Survey only covered 14 of the 31 sites.

The results also indicate that the Client Pathway Survey achieved greatly improved representation of people from *indigenous backgrounds* and people *living in remote areas* of Australia compared with the 2009 Survey of Carers. These improvements can be attributed to the improved participation from the Rocky Ridge site as a consequence of successful implementation of alternative data collection arrangements for their clients (refer Section 3.4).

It is also apparent from the comparison that being from a *CALD background* was not a significant barrier to participating in the surveys. While the proportion of carers from CALD backgrounds was slightly lower for the survey samples than that reported in the SARs, differences in data collection methods and definitions could explain much of the difference.

There are slight differences in the *age and marital status profiles* of survey participants compared with the other two sources. The slightly younger age profile of survey participants is reasonable considering that very elderly people may be somewhat less likely to participate in surveys. Similarly, the slightly lower proportion of widowed care recipients in our surveys may be related to the fact that non-spousal carers tend to be younger (e.g. those caring for a parent) and therefore are likely to have other time-intensive responsibilities such as child-rearing and employment which limit their ability to participate in surveys.

The domain showing least agreement between sources was the proportion of care recipients with *dementia*. These differences may be due primarily to differences in definitions, collection methods, and time of measurement, i.e. carer report (surveys) versus assessment at entry (site data) versus annual reporting (SARs).

Table 5: Comparison of demographic characteristics of carers and care recipients across DDR data sources

Characteristic	Client Pathway Survey (2011) n = 232	Carer Survey (2009) n = 297	Site Data (Jun-Dec 2009) n = 896	SAR data 2009/10 n = 1,427 ¹
Survey Response Rate	42.0%	44.3%		
Gender				
Female – Carers	76.3%	74.1%	74.5%	n.a.
Female – Care recipients	48.3%	50.5%	56.4%	n.a.
Age				
Aged 65+ – Carers	52.6%	54.6%	46.7%	n.a.
Aged 65+ – Care recipients	87.4%	88.9%	92.9%	94.3% ²
Marital status				
Married/Defacto – Carers	80.6%	83.5%	83.9%	n.a.
Married/Defacto – Care recipients	61.2%	65.0%	52.5%	n.a.
Widowed – Carers	4.7%	3.4%	3.1%	n.a.
Widowed – Care recipients	28.0%	26.6%	40.0%	n.a.
CALD background				
Born in a NES country – Carers	16.3%	15.5%	17.3% ³	21.5% ⁴
Born in a NES country – Care recipients	20.7%	19.2%	23.5% ³	22.5% ⁴
Aboriginal/Torres Strait Islander background				
Identified as Aboriginal/TSI – Carers	2.6%	0.3%	3.8%	3.3%
Identified as Aboriginal/TSI – Care recipients	2.6%	0.7%	3.9%	3.2%
Location				
Remote or very remote – Carers ⁵	3.0%	1.0%	3.8%	3.0%

1 There were 1,427 carers and 1,428 care recipients reported for the SARs collection in 2009/10.

2 Aged over 50 years if from an Aboriginal and/or Torres Strait Islander background.

3 Unpublished data from Site Data collection.

4 Defined in SARs as simply 'CALD background'.

5 SARs data regarding location was only available for carers, not care recipients. Also, only the proportion of carers from remote/very remote areas has been compared across sources, as the definition of "rural" was not comparable between SARs and other sources.

Table 6: Comparison of health & service usage characteristics of carers and care recipients across data sources

Characteristic	Client Pathway Survey (2011) n = 232	Carer Survey (2009) n = 297	Site Data (Jun-Dec 2009) n = 896	SAR data 2009/10 n = 1,427 ¹
Carer's self-rated physical health				
Good or higher	62.5%	64.0%	n.a.	n.a.
Fair	28.9%	26.6%	n.a.	n.a.
Poor or Very Poor	6.5%	5.4%	n.a.	n.a.
Care recipients' health conditions				
Dementia	68.5% ²	74.7% ²	32.4% ³	57.1%
Difficult behaviours	12.9%	15.2%	11.2% ³	23.7% ⁴
Frailty/mobility issues	44.8%	48.1%	n.a.	n.a.
Duration of involvement with DDR service				
Less than 6 months	31.1%	35.7%	6.9 months on average	n.a.
Between 6 and 12 months	18.5%	25.9%		n.a.
Between 1 and 2 years	28.9%	32.3%		n.a.
More than 2 years	19.0%	5.7%		n.a.
Exit rate				
Exited from the DDR service	31.5%	n.a.	27.9% ⁵	38.9%
Exit destination of care recipient				
FT High Residential Care	37.0%	n.a.	35.2%	33.7%
FT Low Residential Care	15.1%	n.a.	12.1%	13.9%
Deceased	23.3%	n.a.	16.7%	15.9%

1 There were 1,427 carers and 1,428 care recipients reported for the SARs collection in 2009/10.

2 Higher than recorded in the SARs as the Dementia survey category included general memory loss, i.e. 'Dementia/memory loss'.

3 From a reanalysis of Site data. Note that there was a significant amount of incomplete data for these items, therefore these numbers should be treated with caution.

4 SARs item "Dementia with challenging behaviour" – not directly comparable with survey and site data items.

5 Covers a 6 month period only, rather than a one-year period, and therefore is lower than from other sources.

4.2 ENTRY PATHWAYS

4.2.1 BECOMING AWARE OF THE DDR SERVICE

Carers generally first learned of the DDR service via an *assessment for a Government package, program or service* (27.6%), through a *carer information, support or linkage service* (23.7%) or through *another service or health professional* that they had contact with at the time (21.1% and 19.4% respectively). *Family and friends* were also an important source of information (17.2%). Only a small number of carers had first learned about the DDR service from their *GP* (7.8%) or *through advertising* (7.8%). See Table 7 for details.

Table 7: How carers first became aware of the DDR service

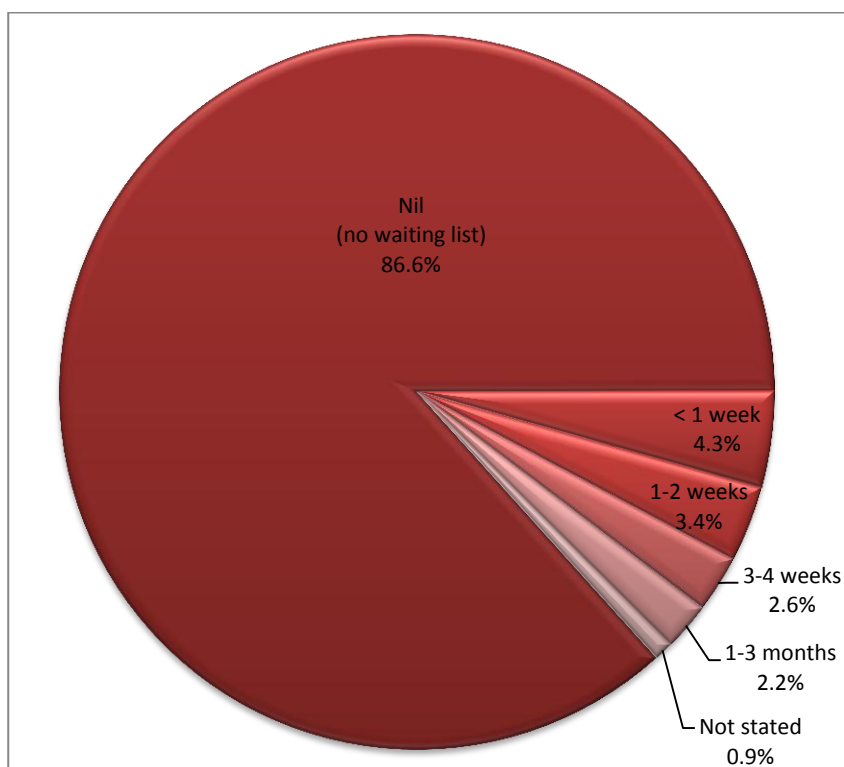
Source	No. of responses	% of respondents ¹
Via an assessment for a Government package, program or service	64	27.6%
Through a carer information, support or linkage service	55	23.7%
Through another service that they were using	49	21.1%
Through another health professional (excluding GPs)	45	19.4%
Through family or friends	40	17.2%
Through their GP	18	7.8%
Through advertising	18	7.8%
Not stated	1	0.4%

¹ Respondents could specify more than one source, therefore the total does not add to 100%.

4.2.2 TIME SPENT ON A WAITING LIST FOR THE DDR SERVICE

Only 12.5% of carers indicated that they had been placed on a waiting list before entering the DDR service. More than half of those had waited for up to two weeks, and the maximum time spent waiting was one to three months – see Figure 14 for details.

Figure 14: Time spent on a waiting list for the DDR service



4.2.3 GOVERNMENT PACKAGES AND PROGRAMS USED BEFORE ENTERING THE DDR SERVICE

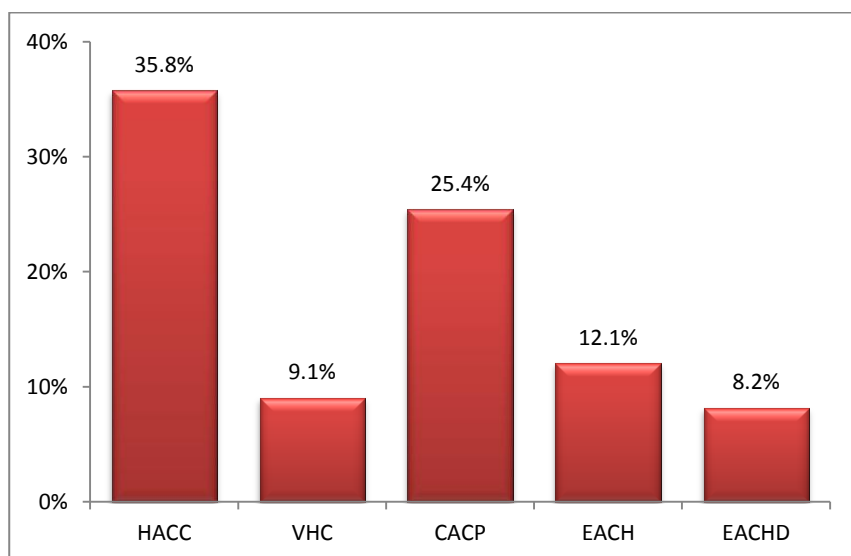
The Survey asked carers to indicate which of the following Government packages and programs, if any, they and the person they cared for (care recipient) had received assistance from *before they started using the DDR service* –

- **Home and Community Care (HACC) program**
The HACC program provides home- and community-based services for people requiring assistance because of disability and/or frailty, and for their carers.
- **Veterans' Home Care (VHC) program**
The VHC program is a Department of Veterans' Affairs (DVA) program designed to assist veterans and war widows/widowers to continue living at home, by providing a small amount of practical help. It is similar to the HACC program.
- **Community Aged Care Packages (CACPs)**
CACP packages are designed to assist older people with complex needs to live at home.
- **Extended Aged Care at Home (EACH) packages**
EACH packages are flexible, individually planned packages of care, which help older people to live at home.
- **Extended Aged Care at Home Dementia (EACHD) packages**
EACHD packages are flexible, individually planned packages of care, designed to help older people who experience difficulties associated with dementia.

Almost two thirds of carers (65.1%) indicated that they and/or the care recipient had used *at least one* of these Government programs or packages before they became involved with the DDR service.

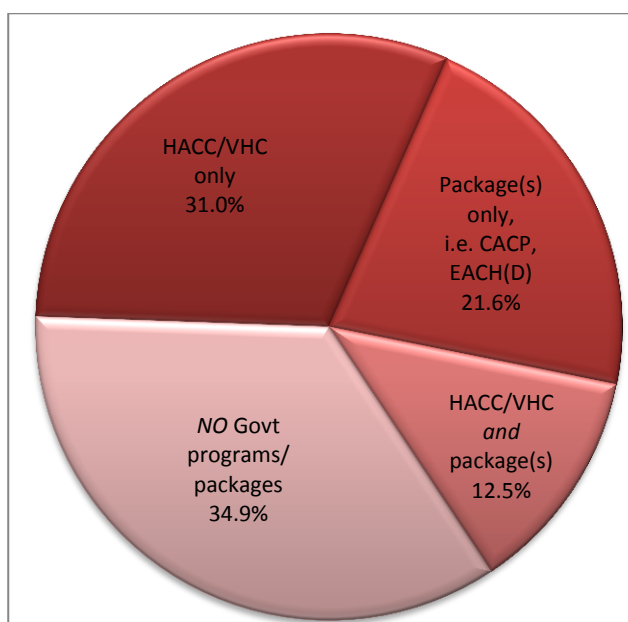
The most commonly used programs/packages prior to entry to DDR services were the HACC program (35.8%) and CACP packages (25.4%) – see Figure 15.

Figure 15: Government programs and packages used before becoming involved with the DDR service



Nearly a third of carers and care recipients (31.0%) had *only* used the HACC and/or VHC program (i.e. had not used any packages) prior to entering the DDR service. A further 21.6% had been using one or more packages (CACP, EACH and/or EACHD) but not HACC/VHC. See Figure 16 for details of the combinations of programs and packages used.

Figure 16: Combinations of programs and packages used before becoming involved with the DDR service



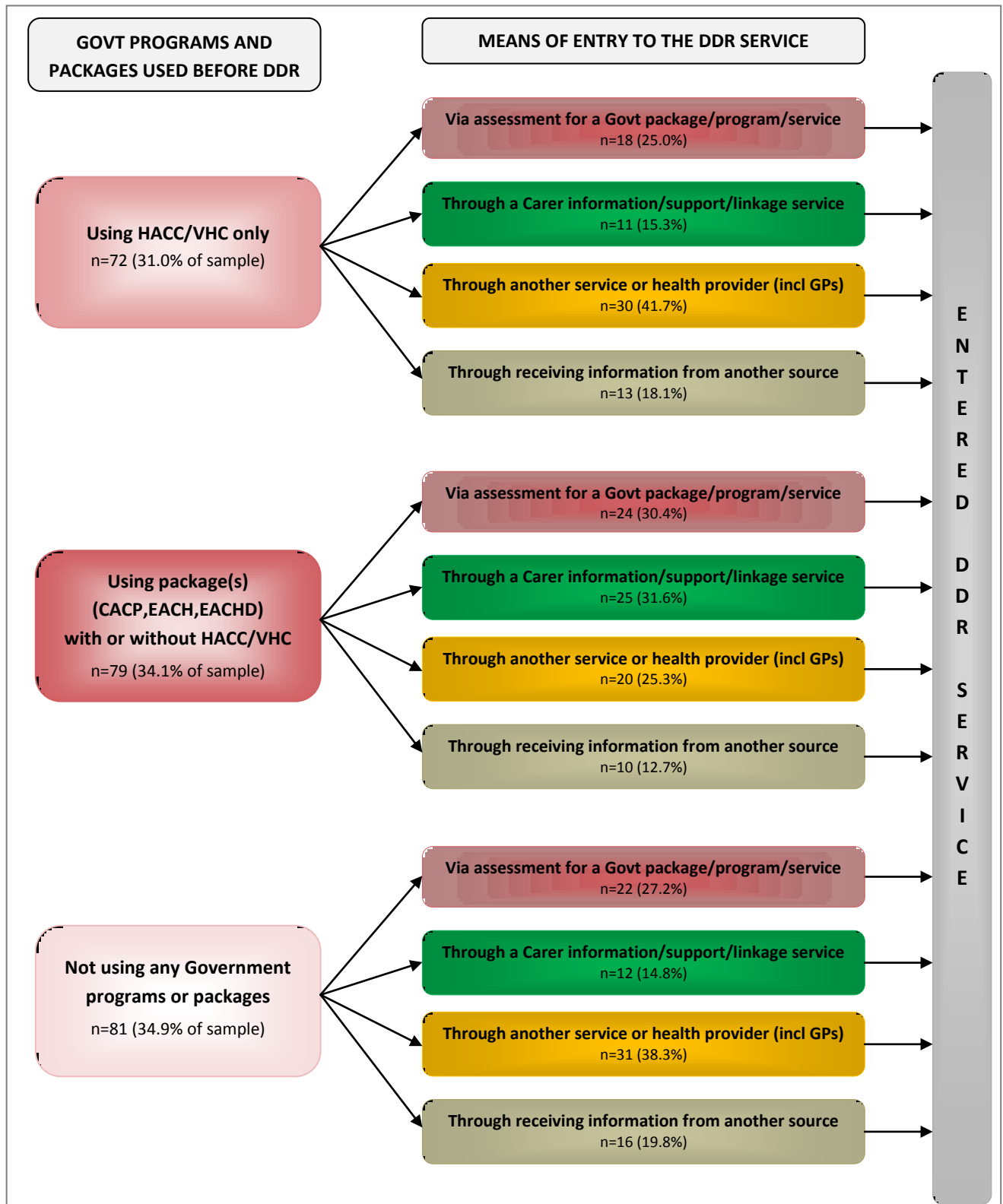
A significantly greater proportion of cases where the care recipient was *frail, unwell or terminally ill* were using at least one Government program/package prior to entering DDR (77.2%), compared with 53.4% of cases where the care recipient was not frail, unwell or terminally ill. However no other demographic or health characteristics of carers or care recipients, including dementia status, were related to the use of programs and packages before DDR.

4.2.4 RELATIONSHIP BETWEEN PACKAGES/PROGRAMS AND MEANS OF ENTRY TO DDR

The relationship between the use of Government programs and packages before entry to DDR and the means by which carers became aware of the DDR service (refer Section 4.2.1) is illustrated in Figure 17.

While the differences did not quite reach statistical significance, it is interesting to note that those who had been using *CACP/EACH/EACHD packages* tended to have heard about DDR either *through an assessment for a program/package* (30.4%) or through a *carer information, support and linkage service* (31.6%), whereas those who had only used *HACC/VHC programs* mostly heard about DDR through *another service or health provider* (41.7%). The most common entry mechanism for those who had *not* been using any government programs/packages was also through *another service or health provider* (38.3%).

Figure 17: Means of entry into the DDR service in the context of Government program/package use



4.2.5 TYPES OF SERVICES USED BEFORE ENTERING THE DDR SERVICE

Carers were also asked to indicate which of the following *types of services* they and the care recipient had used before entering the DDR service –

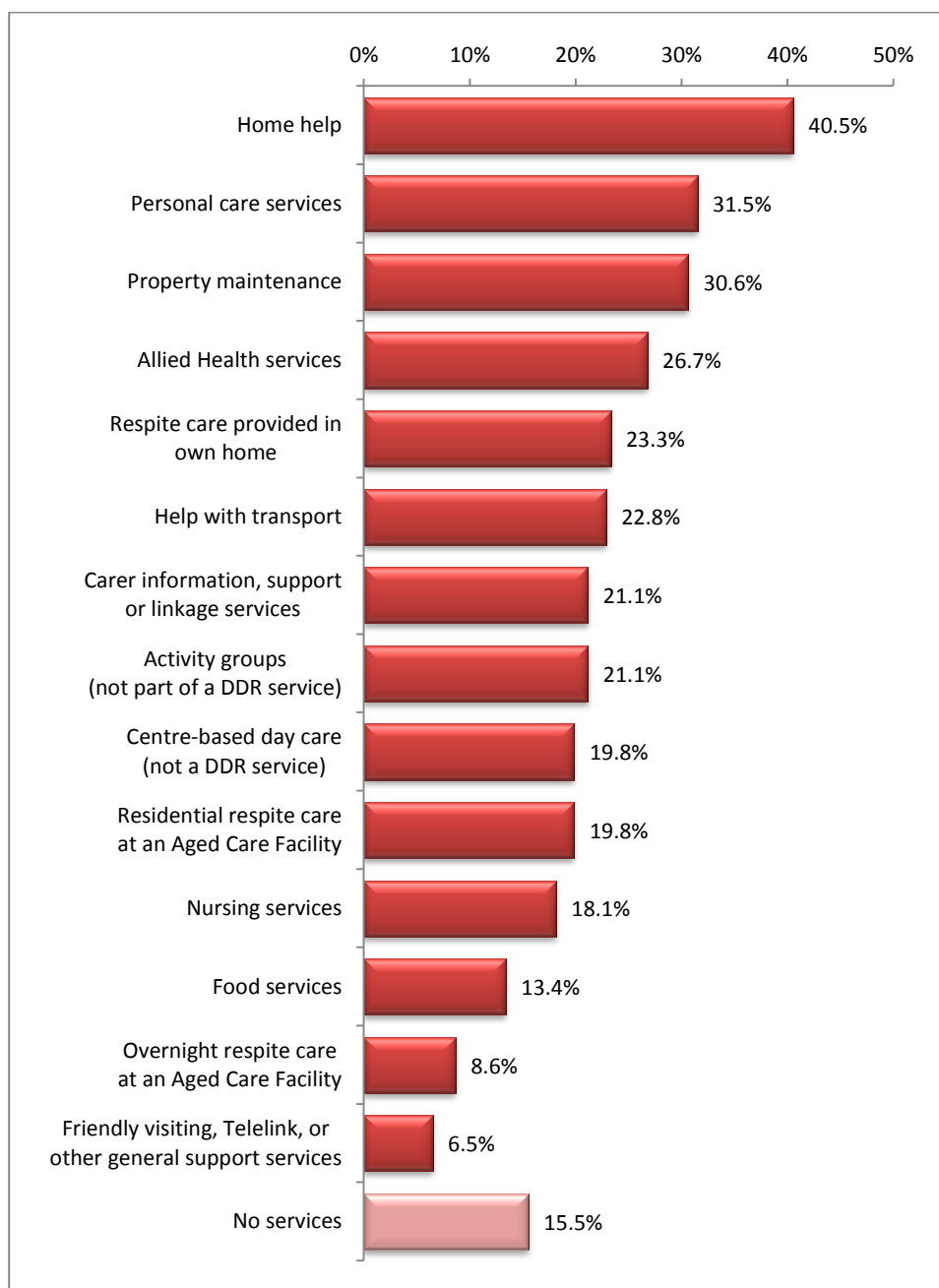
- **Home help**
e.g. cleaning, washing and ironing, help with shopping and errands, help preparing meals and other day-to-day activities within the home.
- **Property maintenance**
e.g. help with maintaining and repairing the home, garden or yard, modifications to the home such as ramps and shower rails.
- **Food services**
e.g. Meals on Wheels or meals at a Centre.
- **Help with transport**
e.g. to get to appointments or to go on outing.
- **Personal care services**
e.g. help with bathing, dressing, grooming, eating, toileting, getting in and out of bed and moving about the house.
- **Nursing services**
e.g. health care delivered by nurses either at home, at a community venue or at a clinic.
- **Allied Health services**
e.g. physiotherapy, podiatry, occupational therapy, counseling.
- **Carer information, support or linkage services**
- **Friendly visiting, Telelink or other general support services**
- **Activity groups (not part of the DDR service)**
e.g. run by other Aged Care Facilities, Church groups, Senior Citizens Clubs.
- **Respite care provided in the home (daytime or overnight), i.e. “in-home respite”.**
- **Other Centre-based day care**
i.e. Day Respite outside the home but not the DDR service.
- **Overnight respite care at an Aged Care Facility**
e.g. one-night stays at an aged care hostel or nursing home.
- **Residential respite care at an Aged Care Facility**
e.g. days or weeks at an aged care hostel or nursing home.

No respondents reported using any other services outside of this list.

As shown in Figure 18, only 15.5% of carers and care recipients *had not used any services* prior to becoming involved with the DDR service. *Home help* was the type of service most commonly used by carers and care recipients (40.5%), followed by *personal care services* (31.5%) and *property maintenance* (30.6%).

In terms of services relating to respite for carers, before becoming involved with the DDR service 23.3% had used *in-home respite care*, 21.1% had used *activity groups*, 18.8% had used a *centre-based day care service*, 19.8% had used *residential respite care at a RACF* and 8.6% had used *overnight respite care at a RACF*.

Figure 18: Types of services used before entering the DDR service, ranked from most to least common

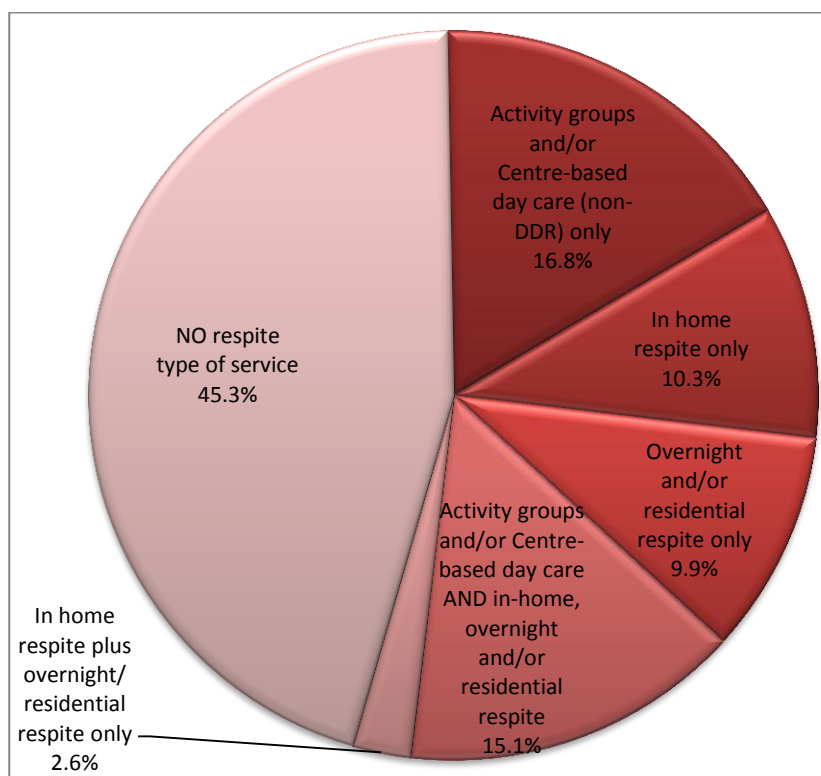


Just under half of carers (45.3%) had not used any *respite services* (i.e. activity groups, centre-based day care, in home respite, overnight respite, residential respite) prior to their involvement with the DDR service. For those who had, many different combinations of those services had been used.

As Figure 19 illustrates, the most common combinations of respite services involved the use of *activity groups* and/or *centre-based day care services*. Nearly 17% of carers had used one or both of those types of service but no other types of respite service, and a further 15.1% had used them in combination with in-home, overnight or residential respite services.

Around 10% of carers had only used *in-home respite services*, and a further 10% had used only *overnight or residential respite care* provided by an Aged Care Facility prior to their involvement with the DDR service.

Figure 19: Combinations of respite services used before entering the DDR service



No demographic or health characteristics of carers or care recipients were associated with the use of respite services in this phase.

4.2.6 ADDITIONAL SERVICES NEEDED PRIOR TO ENTERING THE DDR SERVICE

Nearly a third (30.6%) of carers indicated that in hindsight, additional services would have been helpful in supporting them in their caring role during this period of time. Carers most commonly identified a need for access to, or additional help from, services providing *home help, property maintenance, transport, in-home respite and centre-based day care*.

Many carers reported having been unaware of the existence of some services and experiencing difficulties in finding relevant information about services. For example –

“More information for carers... There are so many packages - I was not aware of the availability and what they covered... Professionals tend to talk in abbreviations - EACH, HACC etc without explaining what they mean.”

“We did not know what was available or where to go for it.”

“Information from someone as to what to do, where to go, and what was available e.g. help for incontinence, products available from govt, medicare, centrelink arrears payment available, etc. Had to find all this out by myself through a friend.”

“Just knowing what services are available would be an enormous help to any carer or for those elderly/disabled people trying to negotiate this web of funded services. There are levels of funding, there are private services, there are programs that exist that are mentioned by some professionals but even the GP has trouble directing the person to how to get the funding or whether the person is eligible. Some services don’t even seem willing to pass on helpful information. While other providers have gone above and beyond to try to answer questions.”

“A booklet on all services relating to caring for the aged etc. would be helpful.”

“Until we started using day respite services we were not informed of all the services available.”

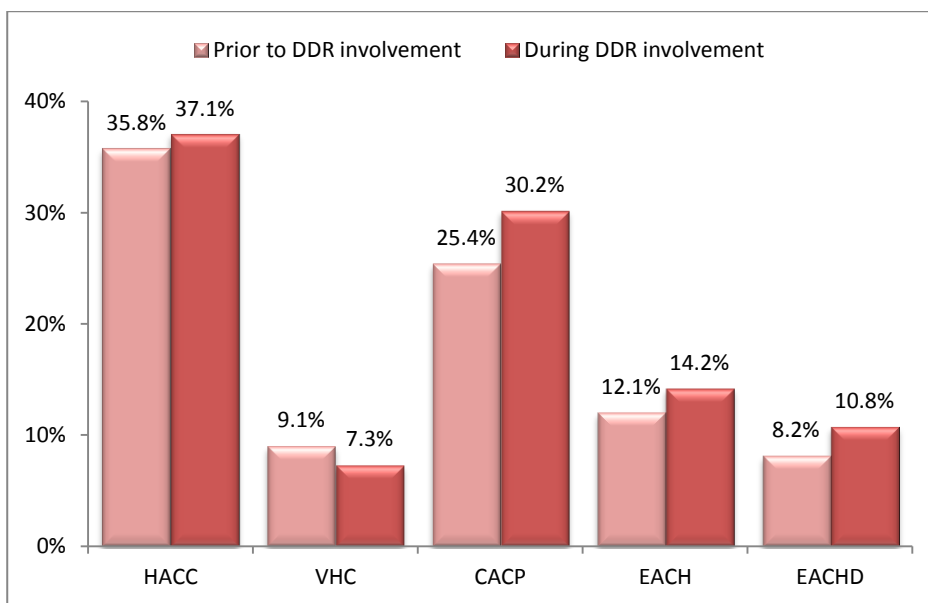
Of those who cited a lack of information about services, most had not been using any services, and none had used any type of respite care, prior to accessing the DDR service.

4.3 PROGRAMS, PACKAGES AND SERVICES USED DURING INVOLVEMENT WITH DDR

4.3.1 GOVERNMENT PACKAGES AND PROGRAMS USED DURING INVOLVEMENT WITH DDR

Overall, the use of Government programs and packages increased only slightly during carers’ involvement with the DDR service – see Figure 20. The changes were not statistically significant.

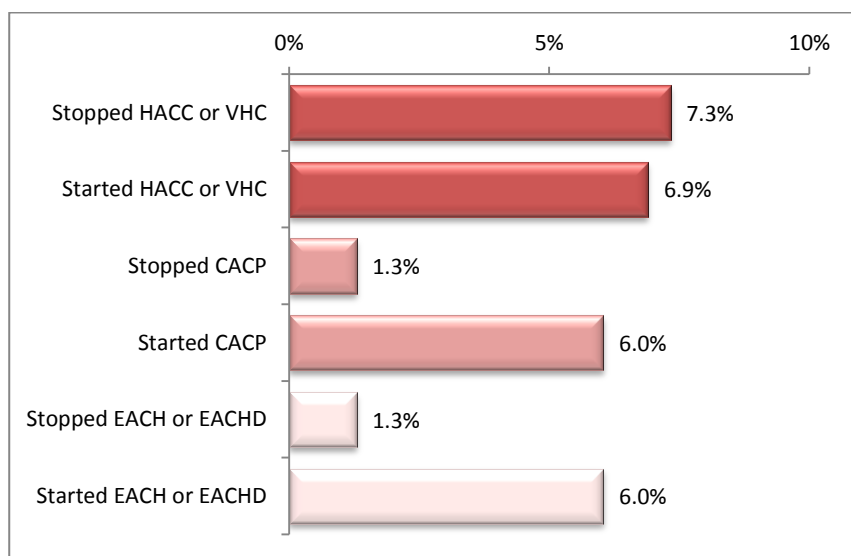
Figure 20: Use of Government programs/packages while involved with DDR compared with prior to DDR



On an individual basis, less than a quarter (23.7%) had changed the Government programs and packages through which they received support. A further half (49.1%) had continued to use the same programs/packages as previously, while the remaining 27.2% did not use any Government packages/programs before nor during their involvement with the DDR service.

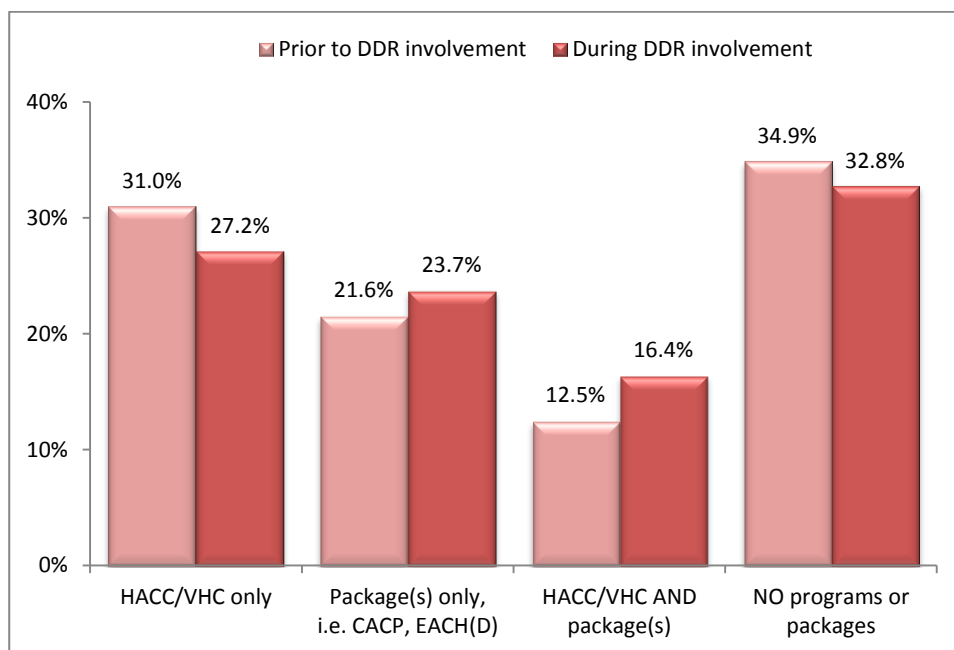
In terms of the nature of changes made, almost equal numbers of individuals had withdrawn from or commenced using HACC/VHC programs during their time with the DDR service, leading to the minimal overall change shown in Figure 20 above. In contrast, the small overall increase in use of CACP and EACH(D) packages was clearly the result of greater take-up of these packages. For details see Figure 21.

Figure 21: Nature of change in use of Government packages/programs after entering DDR



Looking at the combinations of programs and packages used, the overall proportion using *HACC/VHC programs only* decreased slightly after entering the DDR service, while the proportion of those using *packages* alone or in combination with HACC/VHC increased slightly – see Figure 22. However none of these changes were statistically significant.

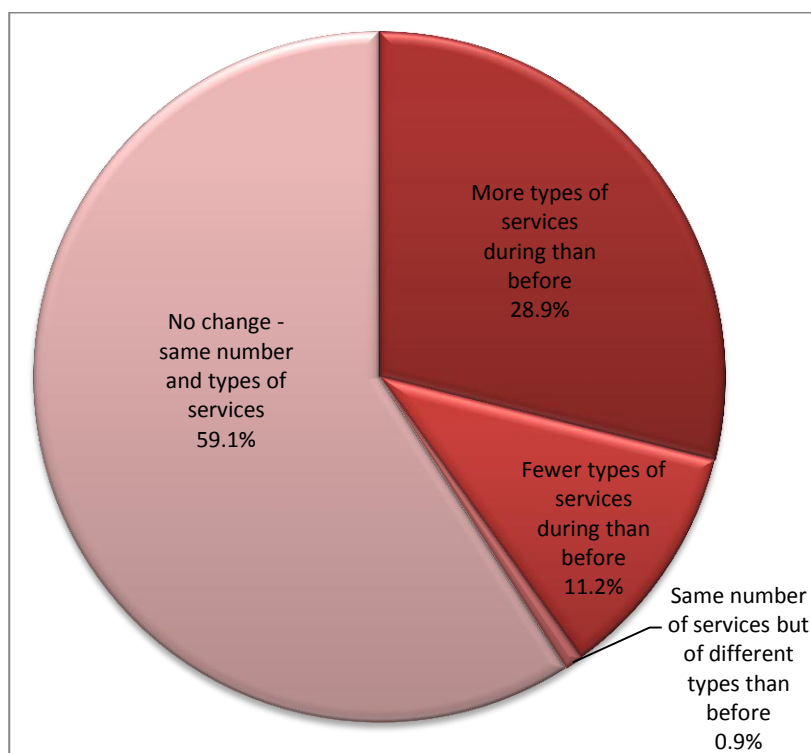
Figure 22: Combinations of programs and packages used while involved with DDR compared with prior to DDR



4.3.2 TYPES OF SERVICES USED IN COMBINATION WITH DDR

After entering the DDR service, over half of carers/recipients (59.1%) continued to use exactly the same number and types of services that they had been using previously. The remainder had made some change – see Figure 23 for details.

Figure 23: Broad changes in service engagement after entering DDR



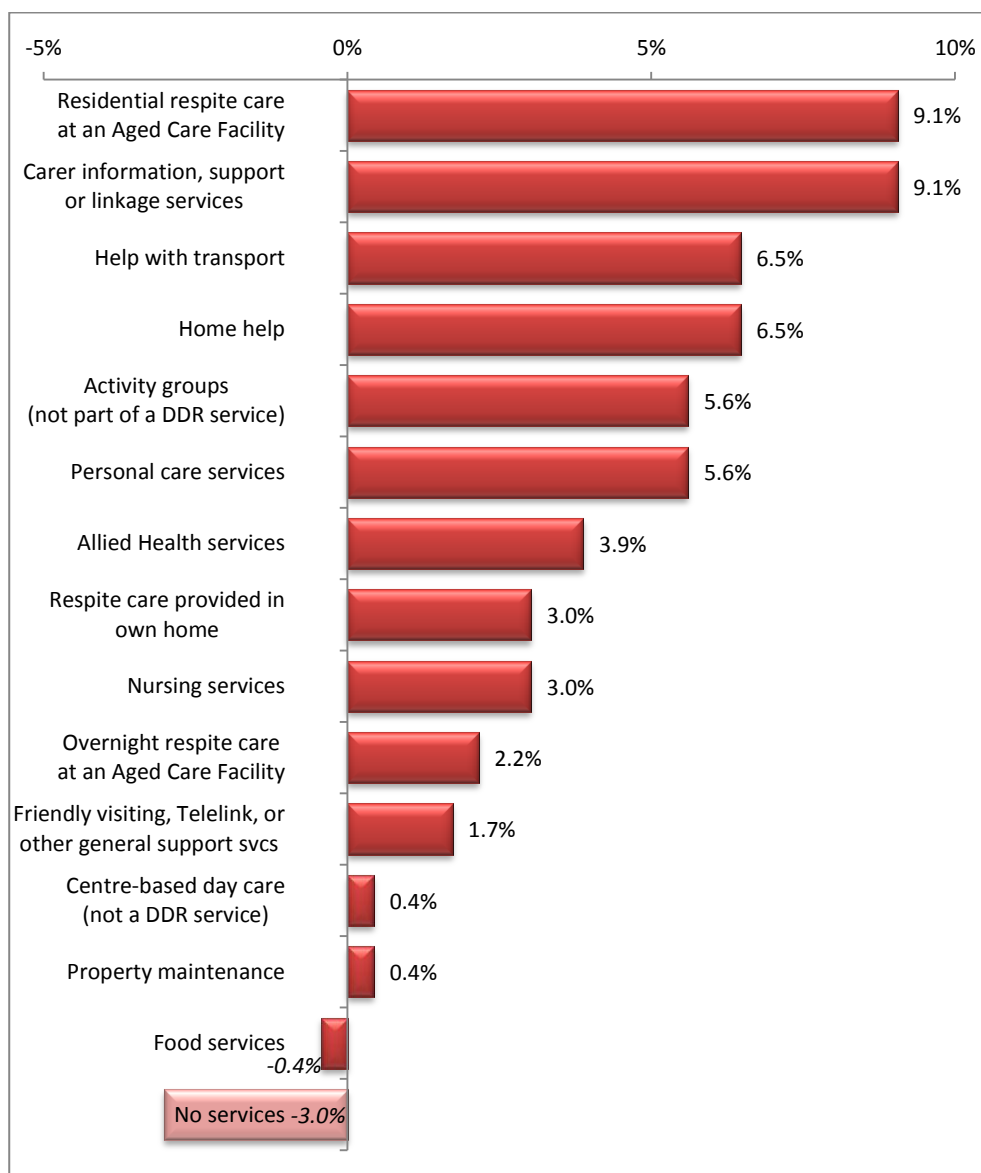
The types of services most commonly *started* after entering DDR were *residential respite at a RACF* (started by 9.5% of carers), *home help services* (9.5%), *personal care services* (9.1%) and *carer information, support and linkage services* (9.1%).

A small number of carers ceased using certain services after entering DDR. The most common cessations were for *property services* (4.3% ceased) and *food services* (3.9% ceased).

The overall change in the proportion of individuals engaged with each type of service is shown in Figure 24. The largest overall increases in engagement occurred for *residential respite care at a RACF* and *carer information, support and linkage services* (increase of 9.1% each). These changes were statistically significant ($p < .01$), as were the changes in use of *transport services*, *home help*, *personal care services* and *non-DDR activity groups* ($p < .05$).

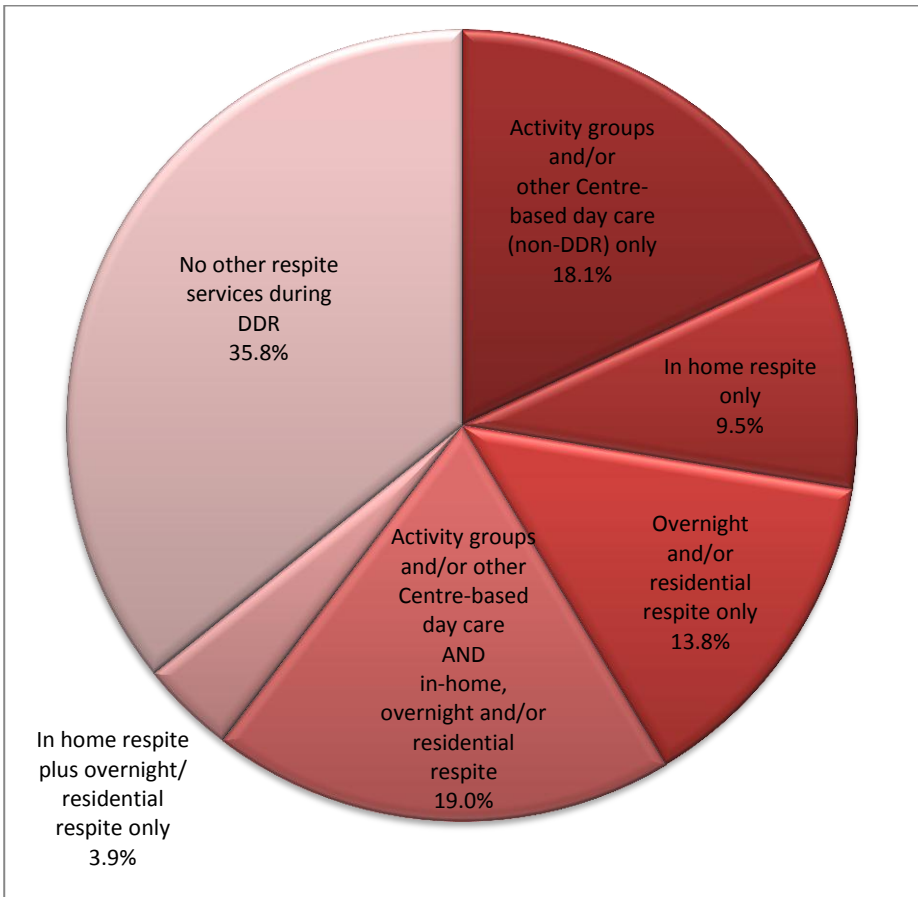
Increased take-up of services, particularly residential respite and carer information/support services, may be at least partly a consequence of information and recommendations provided to carers by the DDR service (refer Section 4.2.6). The increased use of residential respite services may also have been influenced by carers' and care recipients' increased familiarity with and positive experiences within the residential care setting as a result of their involvement with the DDR service. However changes in service use over time will also occur within the context of increasing need for support as both the carer and care recipient age.

Figure 24: Change in engagement with each service type after entering DDR (ranked from greatest to least increase)



At the time of their involvement with DDR, nearly two thirds of carers (64.2%) were also using *other respite services* such as activity groups, other centre-based day care, in home respite, overnight respite and residential respite – see Figure 25. Prior to entering the DDR service only 54.7% of carers had used these other types of respite care. The change was statistically significant ($p < .01$) and was mainly due to carers using *residential respite services* for the first time.

Figure 25: Combinations of other respite services used while involved with the DDR service



No demographic or health characteristics of carers or care recipients were associated with the use of other respite services during involvement with the DDR service.

4.3.3 ADDITIONAL SERVICES NEEDED WHILE USING THE DDR SERVICE

Over three quarters (77.6%) indicated that they had been receiving all the services they needed during their period of involvement with the DDR service. Those who identified a gap most commonly cited a need for additional hours or days from the DDR service.

4.4 EXIT PATHWAYS

4.4.1 REASONS FOR EXIT

The most common reasons given for exiting the DDR service were *entry to full time high level residential care* (37.0%), the *care recipient passing away* (23.3%), *entry to full time low level residential care* (15.1%), or the *care recipient becoming too physically unwell to continue* (11.0%). Reasons suggesting *dissatisfaction with the service or difficulties accessing the service* (i.e. carer dissatisfaction, care recipient refusal, transport issues, cost barrier) were cited by 15.1% of carers who exited the service. See Table 8 for details.

Table 8: Reasons for exit from the DDR service

Reasons for exit from the DDR service	No. of responses	% of those who exited the DDR service ¹
The care recipient entered <i>full time high level residential care</i>	27	37.0%
The care recipient <i>passed away</i>	17	23.3%
The care recipient entered <i>full time low level residential care</i>	11	15.1%
The care recipient became <i>too physically unwell</i> to continue using the service	8	11.0%
The <i>care recipient did not wish to continue</i> using the service	7	9.6%
Found <i>other day respite service(s)</i> that were more appropriate to the carer's/recipient's needs	3	4.1%
Found <i>other types of service(s)</i> that were more appropriate to the carer's/recipient's needs	2	2.7%
<i>Carer was dissatisfied</i> with the service	2	2.7%
The care recipient had <i>behavioural issues</i> that could no longer be managed by the service	2	2.7%
<i>Moved away</i> from the area	2	2.7%
Had difficulty getting <i>transport</i> to/from the service	1	1.4%
Could not afford the <i>cost</i> of the service	1	1.4%
Other reasons not further specified	3	4.1%
Not stated	1	1.4%

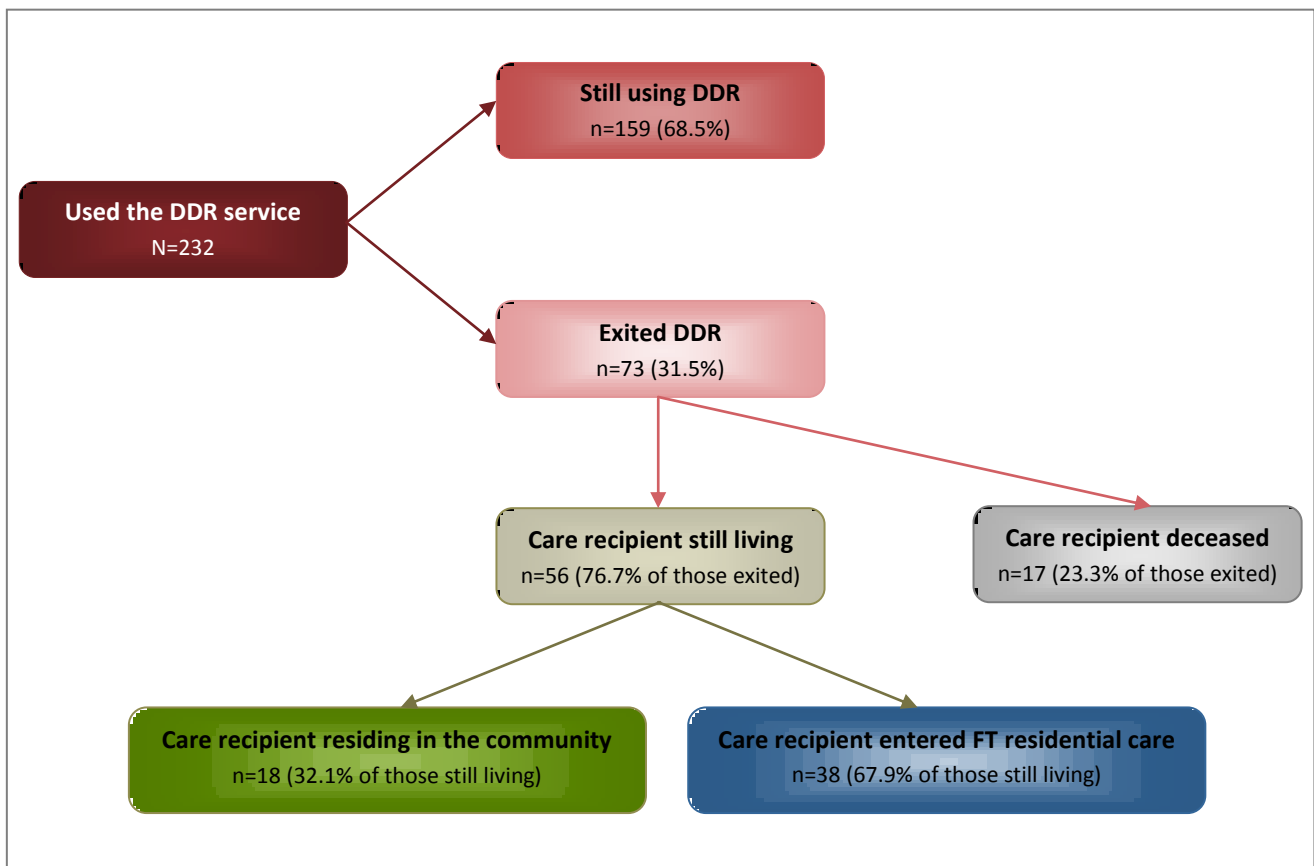
¹ Respondents could specify more than one source, therefore the total does not add to 100%.

Note that two of the care recipients who had exited to full time high level residential care subsequently passed away, leaving 25 care recipients still in high level residential care at the time of the survey. Also, two care recipients who had *not* exited straight to residential care did end up entering low level residential care by the time the survey was conducted.

4.4.2 BROAD EXIT PATHWAYS

The broad exit pathway taken by each respondent was determined by examining the reasons given for exit and the actual services used after exit. As Figure 26 illustrates, by the time of the survey 38 care recipients were in full time residential care, which represented two thirds (67.9%) of those still living after DDR exit and around half (52.1%) of all care recipients who had exited the DDR service. Twenty three percent of all care recipients who exited the DDR service had passed away, while around 25% were still residing in the community.

Figure 26: Diagram showing broad exit pathways for the sample



For the sample as a whole, care recipients with *dementia* were significantly more likely ($p < .05$) to have exited to full time residential care (19.5%) than those without dementia (9.6%). However no other demographic or health characteristics of carers or care recipients were found to influence outcomes.

4.4.3 GOVERNMENT PACKAGES AND PROGRAMS USED AFTER EXITING DDR

All but one of the 17 former carers of deceased care recipients had discontinued all Government programs/packages as a consequence. The exception was an elderly former carer who was using CACP and EACH packages to address their own needs for support.

Less than a third (30.4%) of the remaining 56 carers who had exited DDR were using a Government program or package at the time of the survey. This relatively low overall rate of program/package use (compared with 65.1% before DDR and 67.2% during DDR) was mostly due to many carers relinquishing the day-to-day caring role with the transition of the care recipient into full time residential care. Only 10.5% of carers who had relinquished this role were using Government programs/packages at the time of the survey, compared with 72.2% of cases where the care recipient was still residing in the community.

In terms of the combinations of programs/packages being used after exit from DDR, 12.3% of all carers who had exited DDR were using *HACC or VHC only*, 11.0% were using *CACPs and/or EACH(D) packages only*, and only 1.4% were using both *HACC/VHC and package(s)*. For cases where the care recipient was still residing in the community, just over a third were using HACC/VHC only and a further third were using package(s) only. These results are detailed further in Figure 27.

Figure 27: Combinations of Government packages/programs used after exit from DDR, by exit subgroup

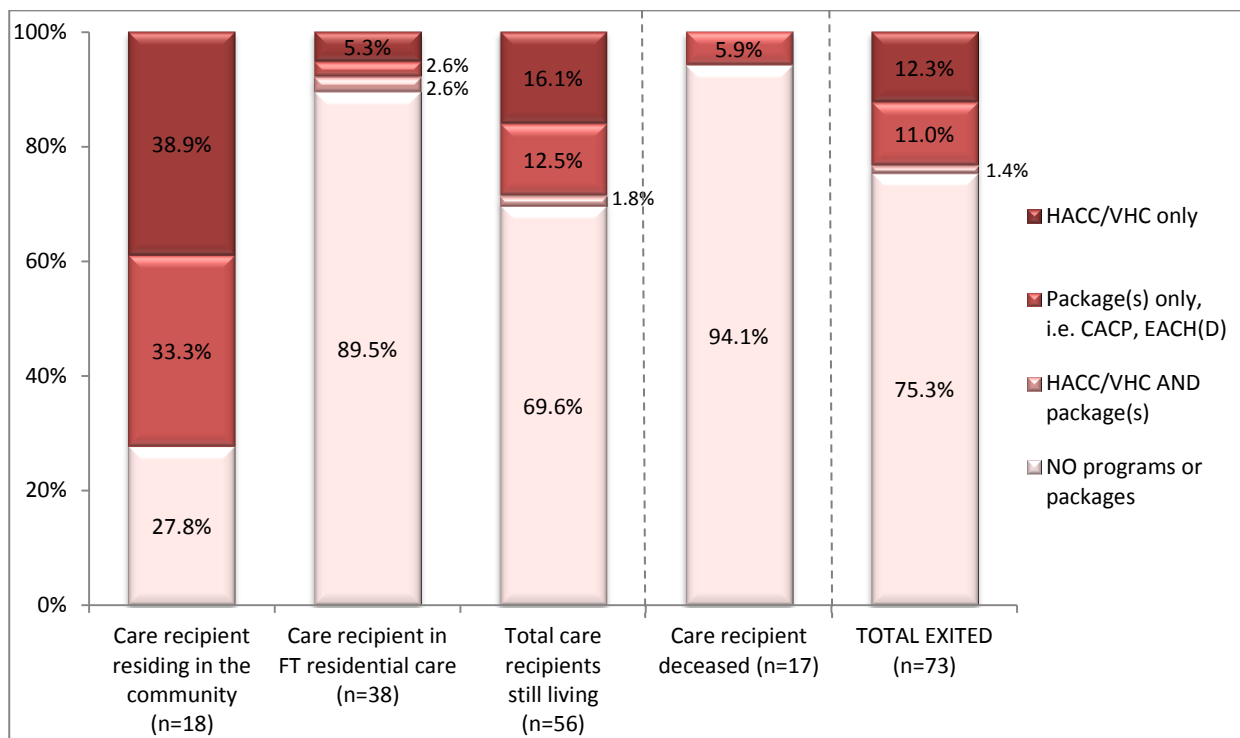
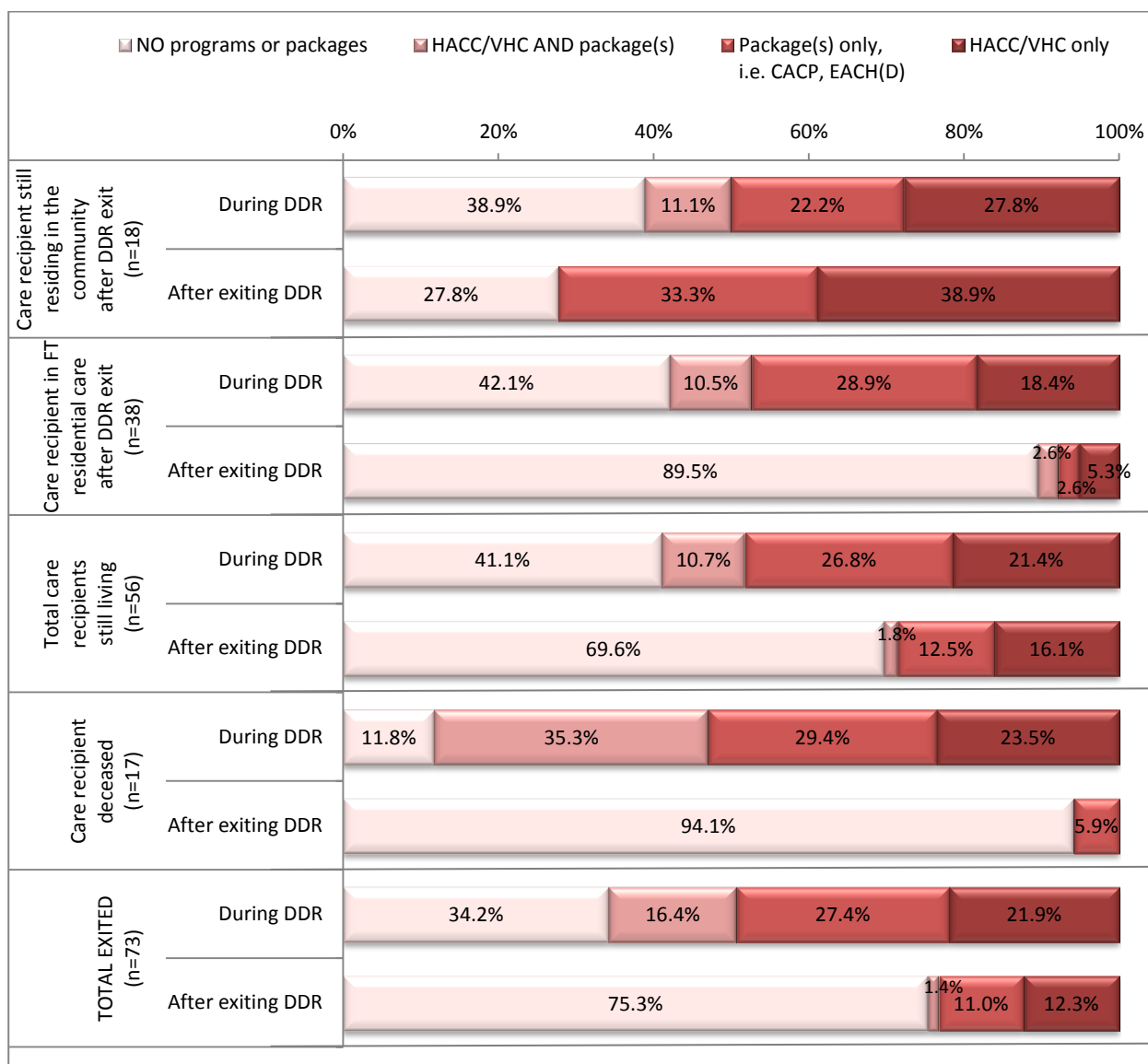


Figure 28 illustrates how the use of Government programs and packages dropped significantly overall for those who had exited DDR ($p < .01$), due to the large proportion of cases where the care recipient had either died or entered full time residential care. The 5-10% of such carers who were still using programs/packages after relinquishing the day-to-day carer role were elderly and had their own needs for supportive services.

For the small group of cases where the care recipient was still residing in the community after exiting DDR (18 cases), there was some additional take-up of both HACC/VHC programs and CACP/EACH(D) packages in the exit phase. This is understandable in the context of the ageing of the care recipient and the ageing of elderly carers. However for this subgroup the change in program/package use was not statistically significant.

Figure 28: Government programs/packages used after exiting DDR compared with during DDR, by exit subgroup



4.4.4 TYPES OF SERVICES USED AFTER EXITING DDR

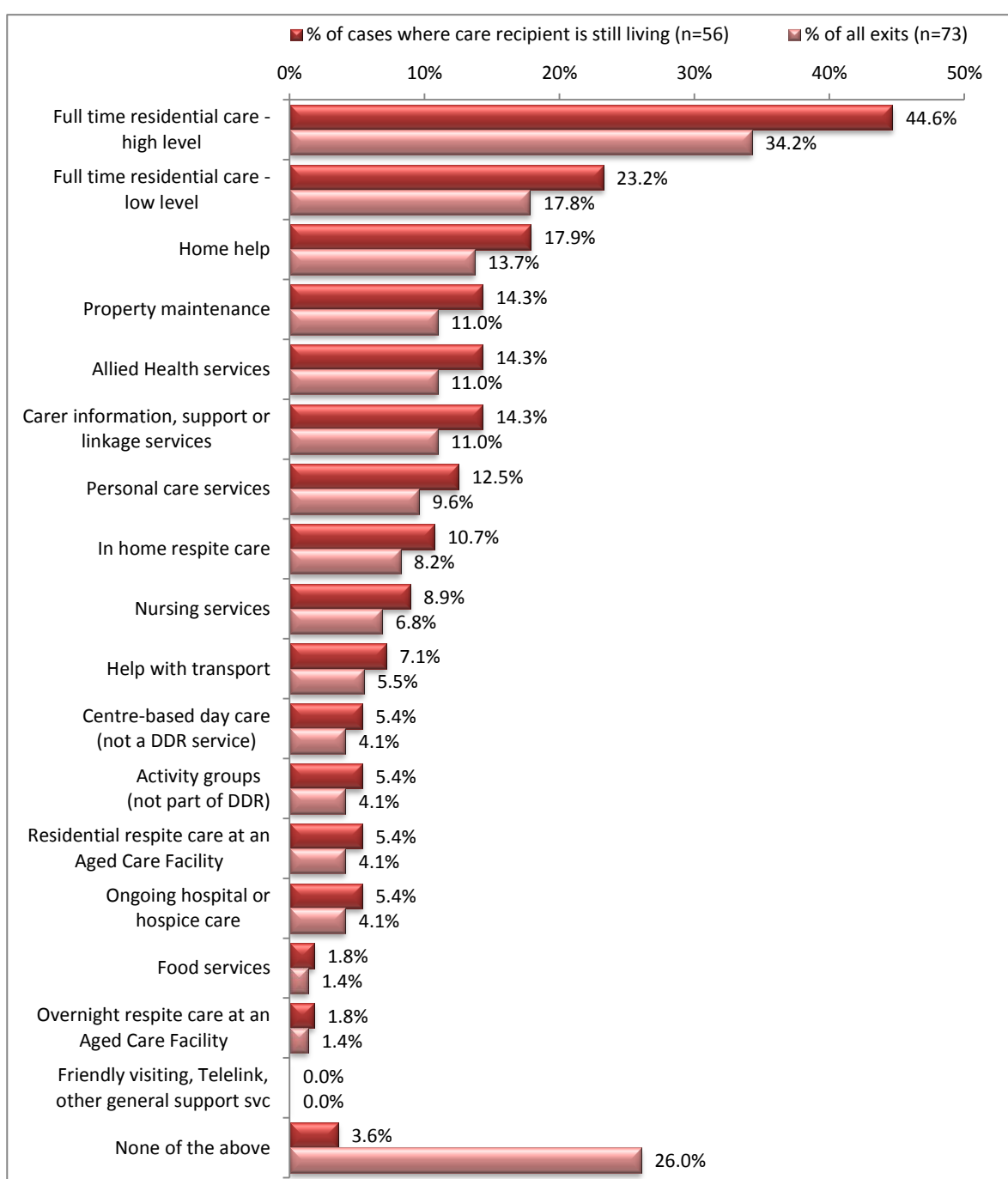
Of particular interest after exit from DDR is the use of full time residential care. As already mentioned, 38 care recipients had transitioned into full time residential care by the time the survey was conducted. Nearly two thirds (65.8%) of these care recipients had entered *high level* residential care. Those entering high level residential care comprised 44.2% of those *still living after DDR exit*, 34.2% of *all those who had exited the DDR service*, and 10.8% of *all those who had used DDR* – see Table 9 for further details.

Table 9: Rates of exit to full time residential care, by type of care

Type of full time residential care	No. of care recipients	% of those who entered FT residential care (n=38)	% of those still living after exiting DDR (n=56)	% of all those who exited DDR (n=73)	% of all those who used DDR (N=232)
High level full time residential care	25	65.8%	44.6%	34.2%	10.8%
Low level full time residential care	13	34.2%	23.2%	17.8%	5.6%
Total full time residential care	38	100.0%	67.9%	52.1%	16.4%

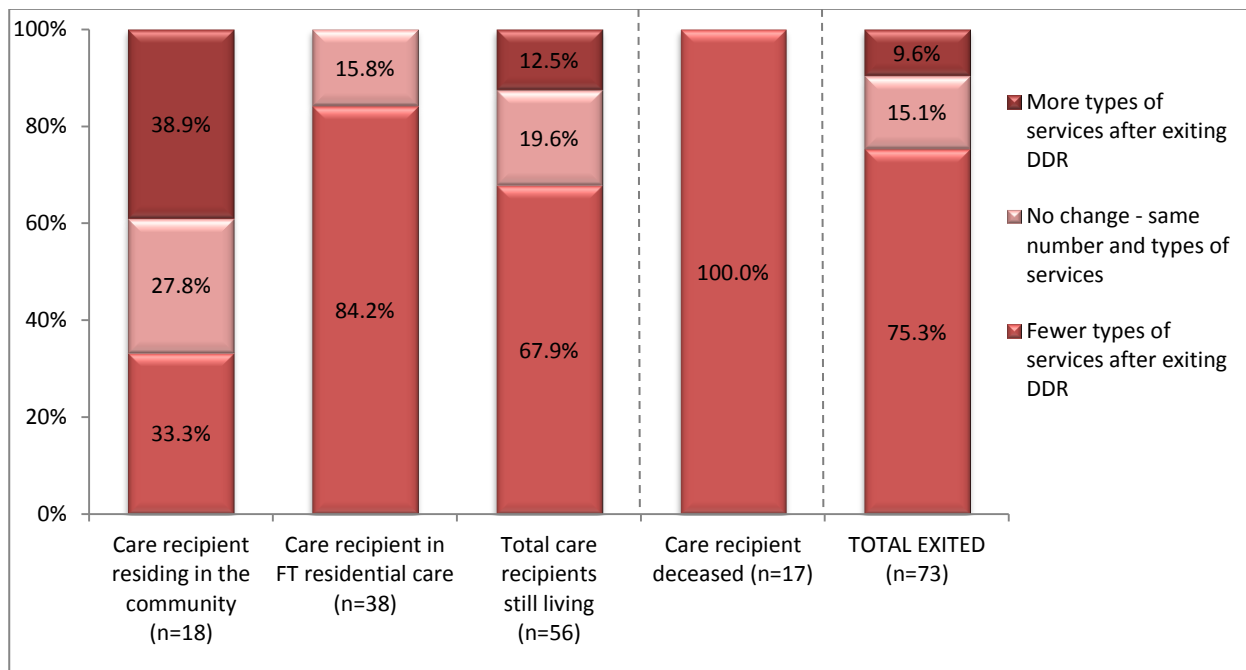
Apart from full time residential care services, the other services most commonly used after DDR exit were *home help* (13.7% of all exits), and *property maintenance, Allied Health services, and carer information, support or linkage services* (all 11.0%) – see Figure 29.

Figure 29: Types of services used after exit from DDR, ranked from most to least common



Looking at broad changes in engagement with services *other than* full time residential care and ongoing hospital/hospice care, overall 75.3% of individuals who had exited the DDR service used *fewer* types of services after exit. As would be expected, almost all of these cases were those where the care recipient had died or had entered full time residential care. See Figure 30 for details.

Figure 30: Broad changes in service engagement after exiting DDR, by exit subgroup



NOTE: Services specific to the exit phase (full time residential care, ongoing hospital/hospice care) were excluded from the calculation of change.

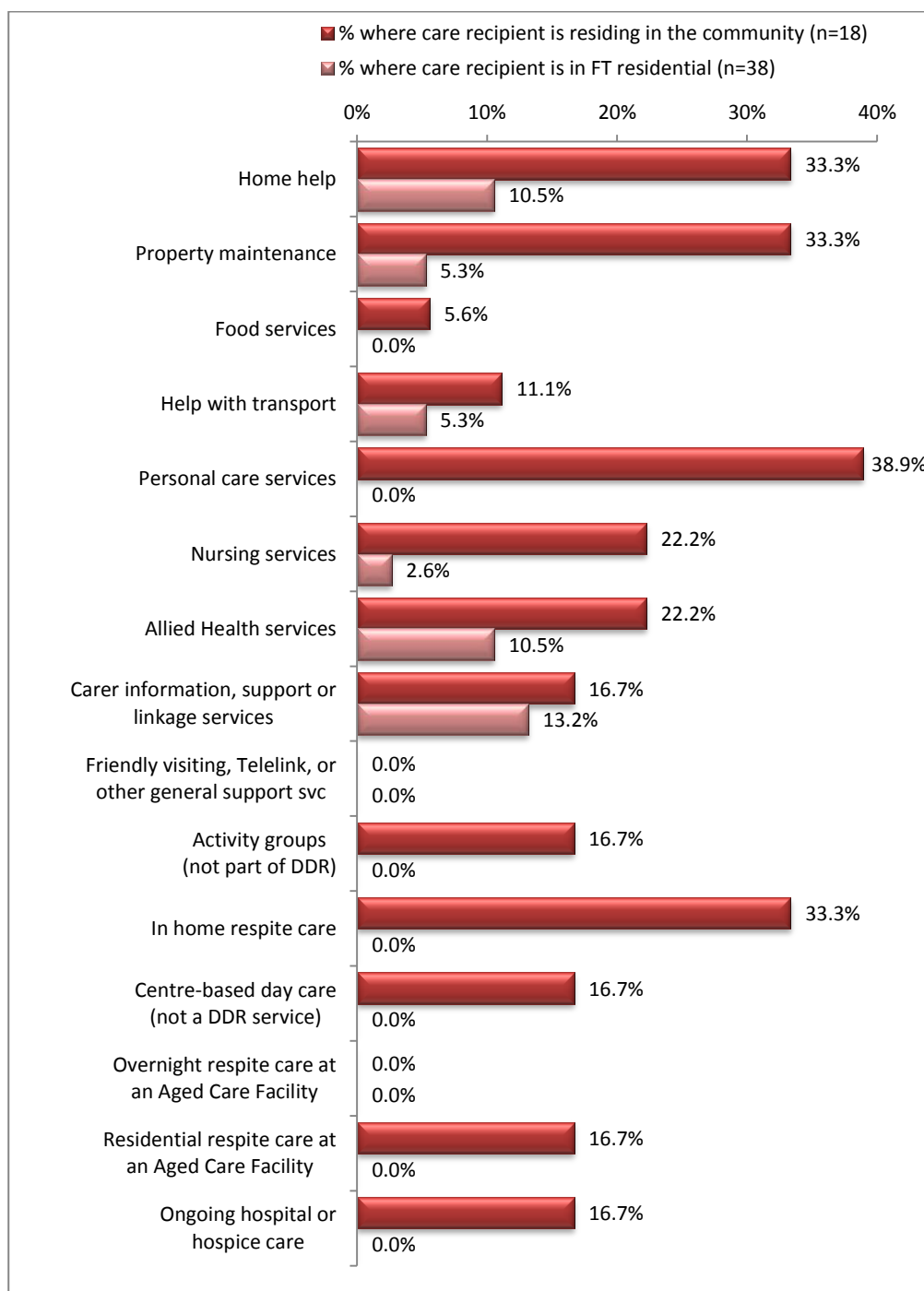
After DDR exit, nearly 90% of carers where the *care recipient was still living in the community* were using at least one non-residential type of service. *Personal care services* (38.9%) and *home help, property maintenance and in home respite care services* (33.3% each) were the types of service most commonly used by this subgroup – see Figure 31. Other forms of *respite* used by this subgroup were *activity groups, centre-based day care and residential respite* (16.7% each).

In total, more than half of these carers (55.6%) were using some type of respite service after DDR exit. *Older carers* (aged 80+) were significantly more likely than younger carers to be using a respite service after exiting DDR, however this was the only demographic or health characteristic to be associated with use of respite services after exit.

As would be expected, service use by former carers of *care recipients in full time residential care* was generally low. Less than a quarter (23.7%) of this subgroup was using any of those services at all after exit from DDR. However *carer information, support and linkage services* were still being used by 13.2% of these former carers, 10.5% were using *home help* and 10.5% were using *allied health services* to address their own needs. It is interesting to note that the proportion of these carers who were using *carer information, support and linkage services* after DDR exit was very similar to that for carers who were still engaged in the day-to-day caring role (13.2% versus 16.7%).

No *carers of deceased care recipients* were using any of the services listed. However three of these carers reported an unmet need for home help and property maintenance services. For further information on the unmet needs reported by carers who had exited the DDR service, see Section 4.4.5.

Figure 31: Service profile of cases where the care recipient was still living after DDR exit



In terms of changes made by individuals in the services they used after exit from DDR compared with the period during their involvement with DDR, there was a slight take up of *personal care services* (11.1% increase), *centre-based day care* (5.6% increase), *residential respite services* (5.6% increase) and *property maintenance services* (5.5% increase) for the small subgroup where the care recipient had continued to reside in the community. However these changes were not statistically significant.

Similarly the proportion of these carers who were using *any non-DDR respite service* had not changed significantly after exiting DDR (55.6% after DDR versus 50.0% during DDR), nor had there been any significant change in the combinations of respite services they used. This indicates that exit from DDR to the community did *not* result in significant take up of other respite services, at least by the time the survey was conducted.

4.4.5 ADDITIONAL SERVICES NEEDED AFTER EXITING DDR

Only fourteen (19.2%) of the 73 carers who had exited the service indicated that some additional services would be useful to them at the present time. Half of these carers expressed a need for *home help* and/or *property maintenance* services, and just three carers stated a need for additional *respite* or *carer support* services. One carer of a recipient who had entered full time residential care made an interesting suggestion regarding a visiting service for nursing home residents –

“Since I have a young family and a job, it is difficult to visit [the care recipient] frequently. I would appreciate a service whereby you could employ a caring person to call in to the Residential Aged Care to visit and check all is fine once or twice each week so [the care recipient] can get more than 2 visits (from me) each week.”

4.5 ENTIRE PATHWAYS

The preceding sections have examined in detail the programs, packages and services used at different points along the pathway into and out of DDR. The extent of change across each time point, the statistical significance of those changes, and any variables influencing those changes, has also been reported. In summary, these analyses have shown that –

- There was a small additional take up of *Government programs and packages* by individual carers after entering DDR and again after exiting DDR (where the care recipient was still residing in the community), but these changes were not statistically significant.
- In terms of the *types of services* used over time, carers’ engagement with personal care services, transport services, home help, residential respite care services, non-DDR activity groups, and carer information/support and linkage services increased significantly after entering DDR, but not after exit to the community.
- Exit from DDR to the community had *not* resulted in significant uptake of *other respite services*, at least by the time of the survey. Most of these carers had continued to use the same non-DDR respite services after leaving DDR as they had while using DDR.
- Given the high proportion of exits from DDR due to care recipients’ transition to full time residential care (52.1%) or death (23.3%), there was a *net overall decrease* in the use of programs, packages and services after exit from DDR.
- The demographic and health characteristics of carers and care recipients did not exert a systematic influence on the changes seen across the pathway. However there were some localized differences as follows – cases where the care recipient was *frail, unwell or terminally ill* were more likely to be using Government programs and packages *prior to entering DDR*; cases where the care recipient had *dementia* were more likely to exit to *full time residential care*; and *older carers* were more likely to use *respite services after exit* to the community.

This section takes a different view by illustrating the *range of pathways* taken over time as the sample of carers progressed across the three phases of their journey – before DDR, during DDR, and after DDR.

4.5.1 PROGRAM/PACKAGE PATHWAYS

Table 10 below summarises the use of Government programs and packages across each phase of the carer journey, and illustrates how program/package use after exit is primarily driven by the exit destination of the care recipient.

Table 10: Summary of Government program/package use across the carer journey

Government program/package	BEFORE DDR	DURING DDR	AFTER DDR			
	% of total (n=232)	% of total n=232	% of all who exited (n=73)	% where recipient still living after exit (n=56)	% where recipient entered FT residential care (n=38)	% where recipient residing in community after exit (n=18)
Individual programs/packages						
HACC	35.8%	37.1%	11.0%	14.3%	7.9%	27.8%
VHC	9.1%	7.3%	2.7%	3.6%	0.0%	11.1%
CACPs	25.4%	30.2%	8.2%	10.7%	5.3%	16.7%
EACH	12.1%	14.2%	11.0%	14.3%	2.6%	0.0%
EACHD	8.2%	10.8%	5.5%	7.1%	2.6%	16.7%
Combinations of programs and packages						
HACC and/or VHC only	31.0%	27.2%	12.3%	16.1%	5.3%	38.9%
Package(s) (CACP, EACH, EACHD) only	21.6%	23.7%	11.0%	12.5%	2.6%	33.3%
HACC/VHC and package(s)	12.5%	16.4%	1.4%	1.8%	2.6%	0.0%
No programs or packages	34.9%	32.8%	75.3%	69.6%	89.5%	27.8%

While useful in terms of quantifying net changes in usage over time, the full range of different pathways is obscured when this is the sole method used to present the data. Therefore the differential pathways taken by subgroups of carers, in terms of the combination of programs and packages they used in each phase of their journey, are illustrated in the following set of three diagrams –

- Figure 32: Government program/package use pathways for those who were only using HACC/VHC before entering the DDR service;
- Figure 33: Government program/package use pathways for those who were using Package(s) +/- HACC/VHC before entering the DDR service; and
- Figure 34: Government program/package use pathways for those who were not using any programs or packages before entering the DDR service.

As evident from the titles of these diagrams, each covers one of the three main starting points in terms of program/package combinations reported by the sample. The set of diagrams covers all 232 respondents.

The diagrams illustrate a general trend of continuity in the Government programs/packages used by individuals before and during entry to the DDR service, and extending to the post-exit phase for cases where the care recipient had continued to reside in the community. Commonly, carers/recipients kept using the same programs and packages until the care recipient had either passed away or had entered full time residential care. Where programs or packages were being used after those outcomes, they had been granted to carers in their own right to maintain their own independent living.

For cases where there were changes in the programs/packages used across the pathway, the direction of change was usually towards additional or more intensive types of program/package, i.e. from nil to at least one type of program/package, or from using HACC/VHC programs in isolation towards using packages as well as or instead of HACC/VHC.

Note that there are some cases where probable inconsistencies are evident in carers' reporting of the programs/packages they used at each time point. For example, one carer reported using *package(s) +/- HACC/VHC* prior to DDR entry, *no programs/packages* during DDR entry, but then *package(s) +/- HACC/VHC* again after exit. However these cases are very much in the minority.

Figure 32: Government program/package use pathways for those who were *only using HACC/VHC* before entering the DDR service

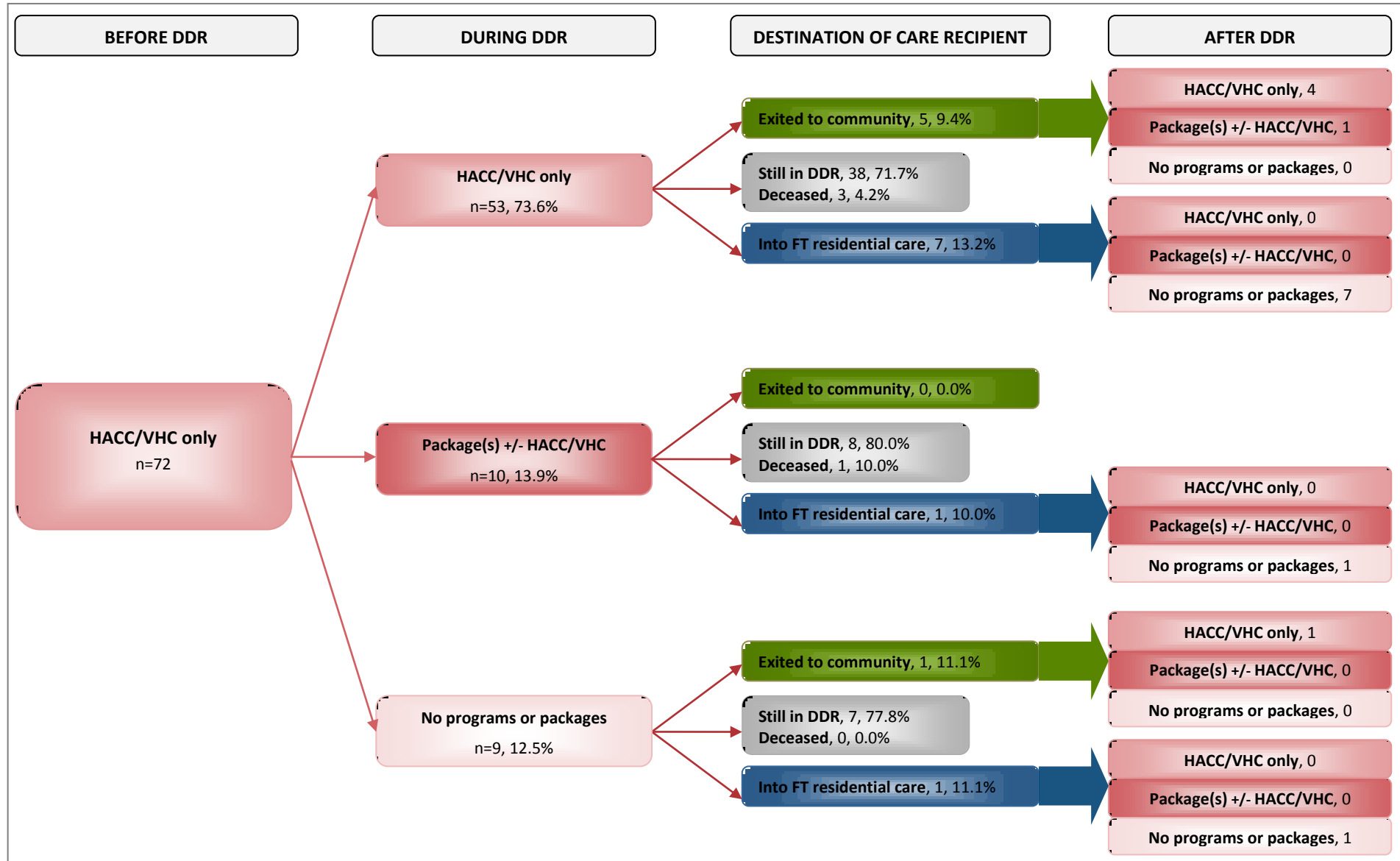


Figure 33: Government program/package use pathways for those who were using *Package(s) +/- HACC/VHC* before entering the DDR service

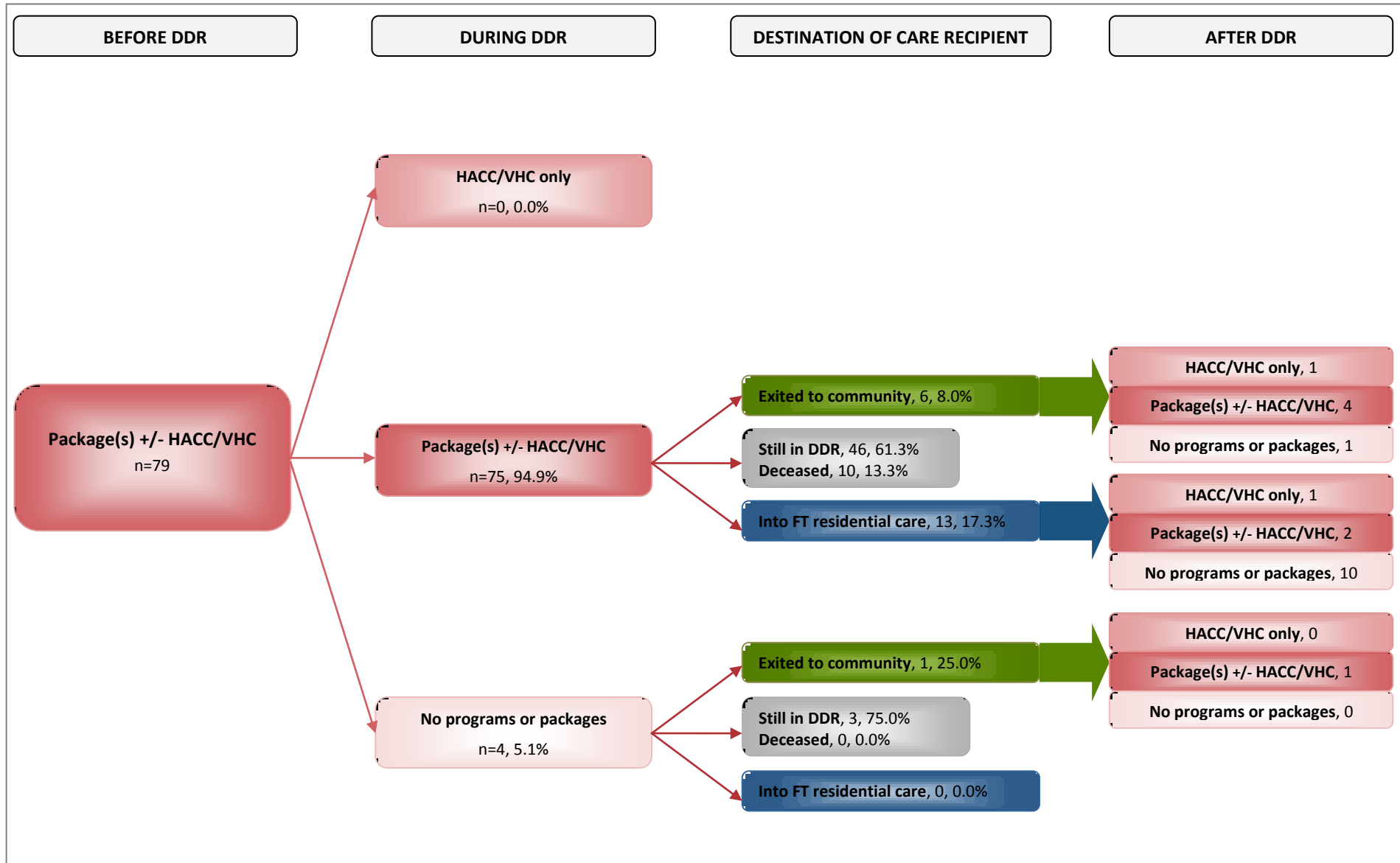
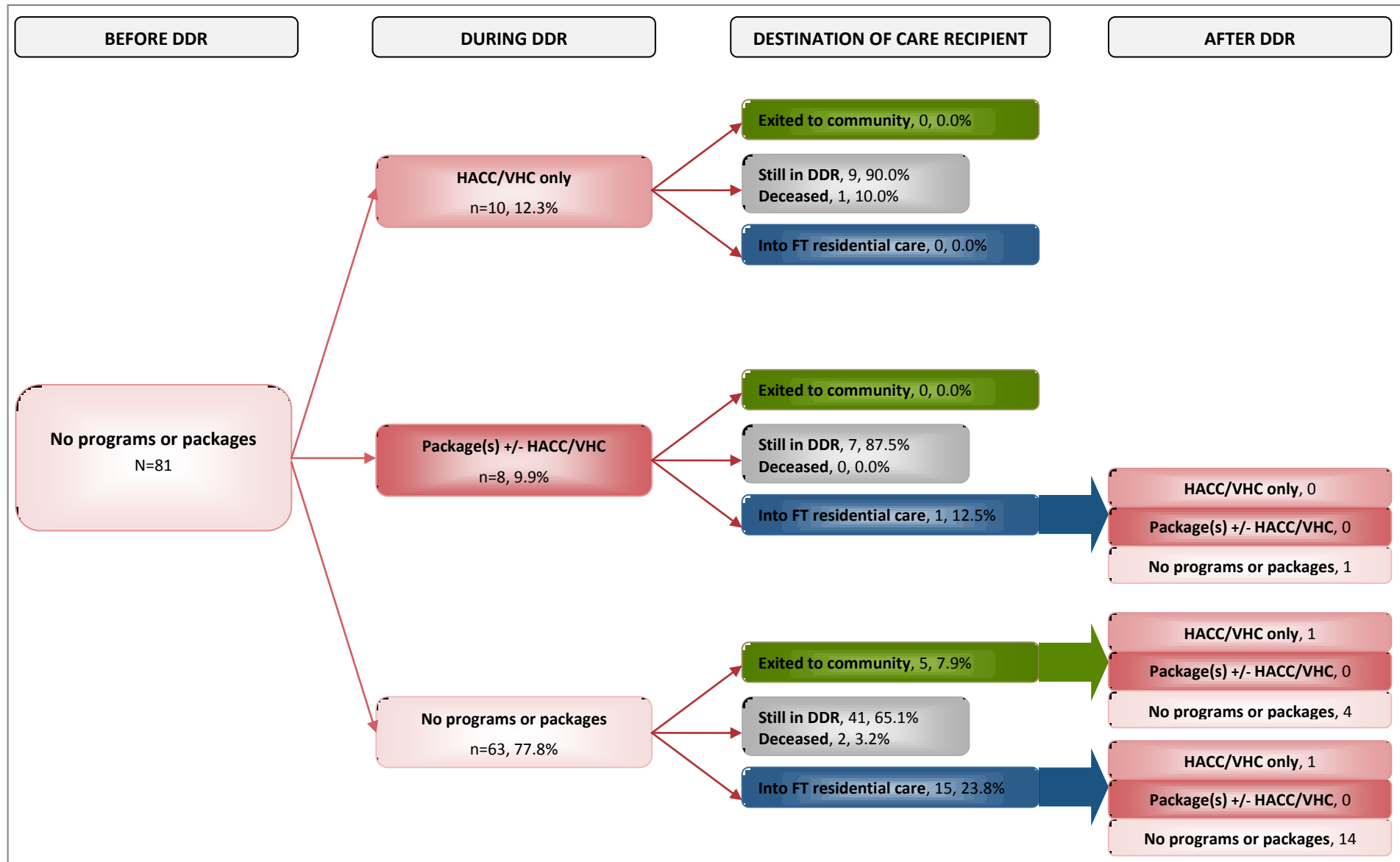


Figure 34: Government program/package use pathways for those who were *not using any programs or packages* before entering the DDR service



4.5.2 RESPITE SERVICE PATHWAYS

In terms of all the different types of services used by carers, those of greatest interest to this analysis are the *respite services* that carers used instead of, or in addition to, the DDR service. Table 11 below summarises the use of these respite services across each phase of the journey through DDR. For the post-DDR period, respite service use is shown only for the subgroup of cases where the care recipient was *still residing in the community* after exiting DDR, since carers of people who had passed away or had entered full time care had consequently ceased using respite services.

Table 11: Summary of the use of non-DDR respite services across the carer journey

Non-DDR respite services	BEFORE DDR	DURING DDR	AFTER DDR
	% of total (n=232)	% of total n=232	% where care recipient was residing in the community after exit (n=18)
Individual respite services			
Activity groups	21.1%	26.7%	16.7%
Centre-based day care (non-DDR)	19.8%	20.7%	16.7%
In home respite	23.3%	26.3%	33.3%
Overnight respite at a RACF	8.6%	10.8%	0.0%
Residential respite at a RACF	19.8%	28.9%	16.7%
Combinations of respite services			
Activity groups or Centre-based day care only	16.8%	18.1%	44.4%
In home, overnight or residential respite	22.8%	27.1%	11.1%
Combination of the above	15.1%	19.0%	27.8%
No respite services	45.3%	35.8%	16.7%

The differential pathways taken by subgroups of carers, in terms of the combination of respite services they used in each phase of their journey, are illustrated in the following set of four diagrams –

- Figure 35: Respite service pathways **for those who were only using Activity groups/Centre-based Day Care before entering the DDR service;**
- Figure 36: Respite service pathways **for those who were only using in home, overnight and/or residential respite before entering the DDR service;**
- Figure 37: Respite service pathways **for those who were using a combination of Activity groups/Centre based day care and in home/overnight/residential respite before DDR;** and
- Figure 38: Respite service pathways **for those who did not use any respite services before entering the DDR service.**

As evident from the titles of these diagrams, each covers one of the four main starting points in terms of the combinations of respite services used by the sample. The set of diagrams covers all 232 respondents.

Again, these diagrams illustrate a general trend of continuity over time in the types of non-DDR respite services used by individual carers. Most carers had continued to use the same types of respite services as they had prior to entering the DDR service, until the care recipient had either passed away or entered full time residential care. Where there had been changes over time, these were mainly in terms of either engaging with a (non-DDR) respite service for the first time, using more resource-intensive types of respite such as in home respite and residential respite, or using a broader combination of respite types over time.

Figure 35: Respite service pathways for those who were *only using Activity groups/Centre-based Day Care* before entering the DDR service

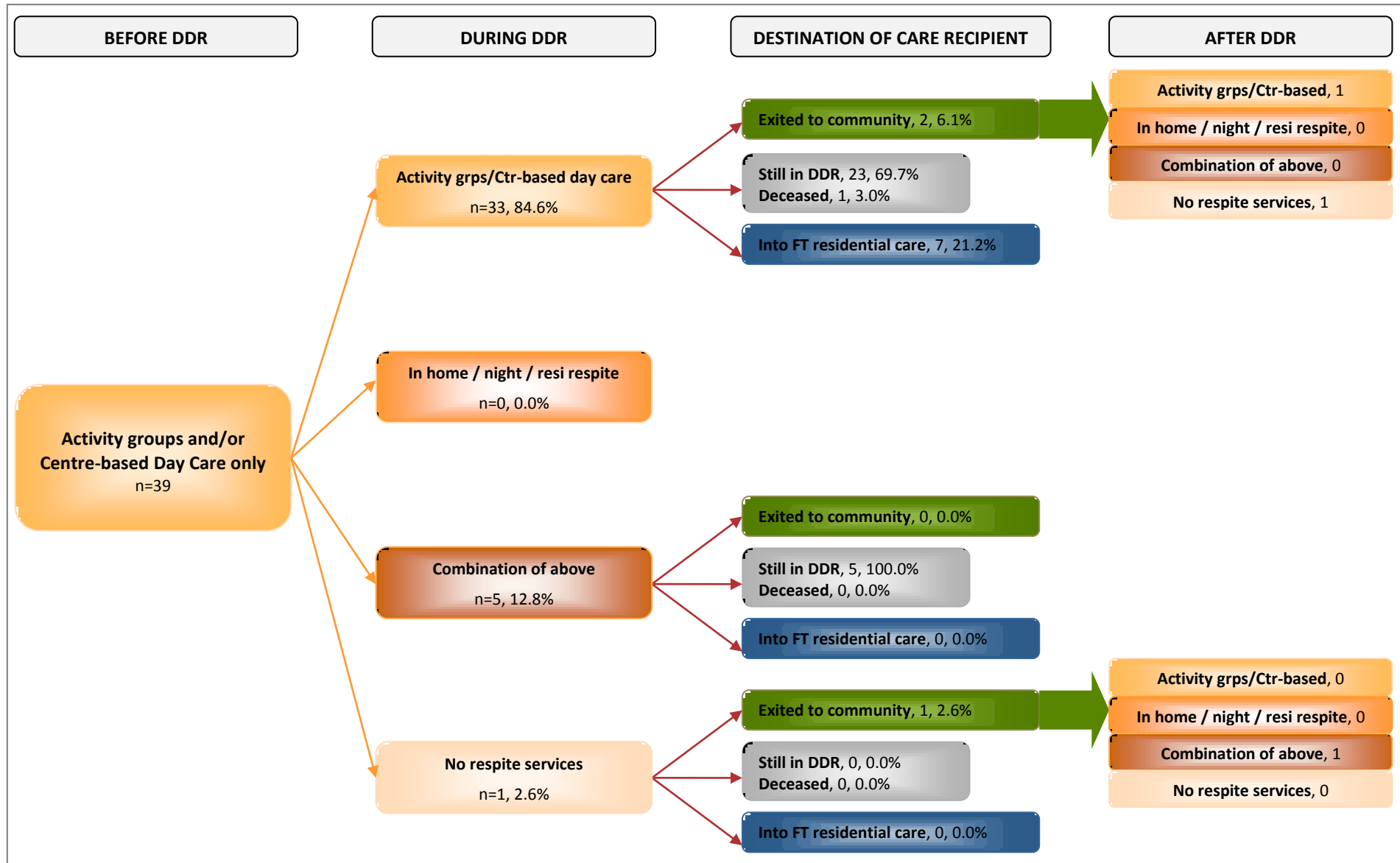


Figure 36: Respite service pathways for those who were only using *in home, overnight and/or residential respite* before entering the DDR service

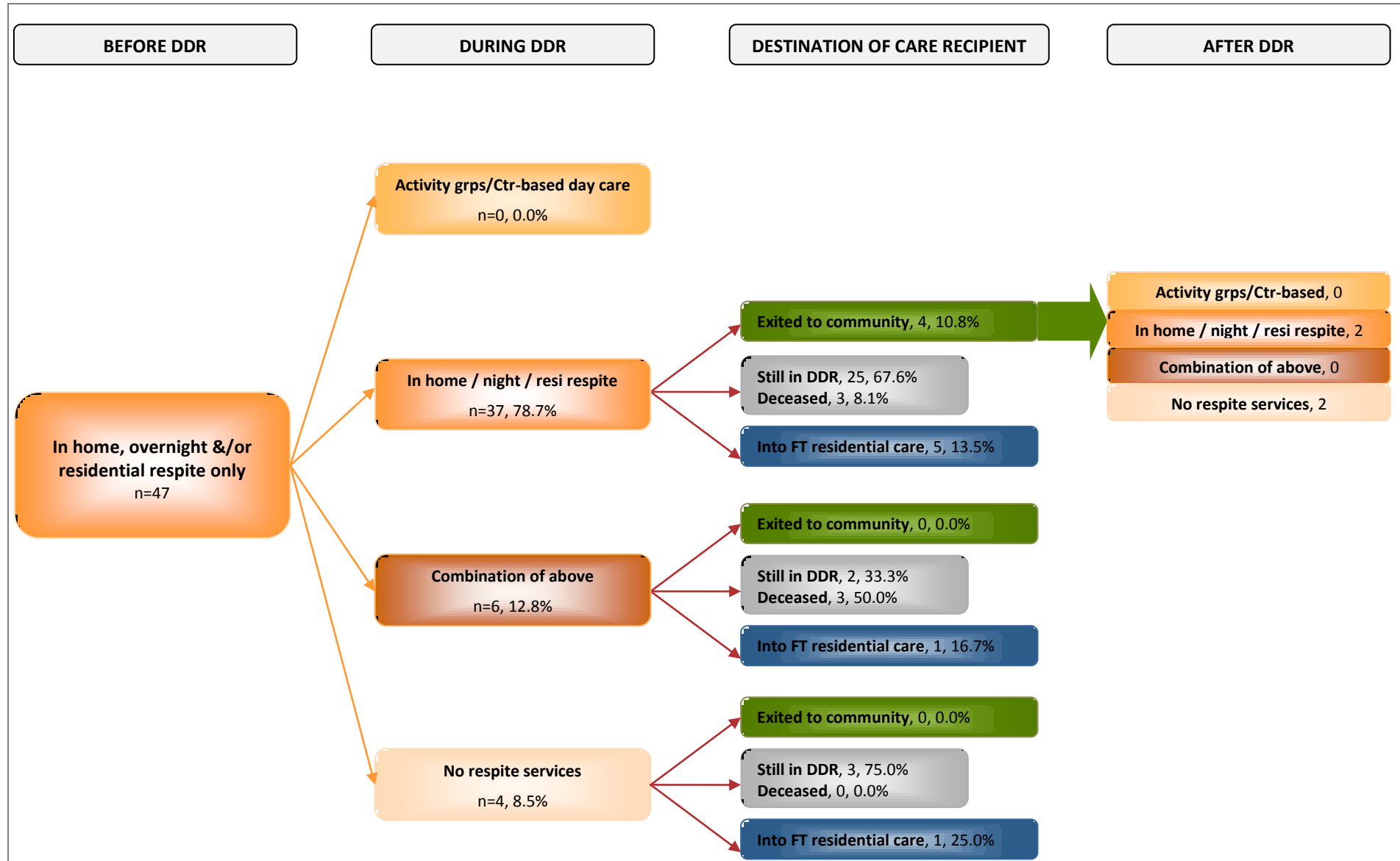


Figure 37: Respite service pathways for those who were using a combination of Activity groups/Centre based day care and in home/overnight/residential respite before DDR

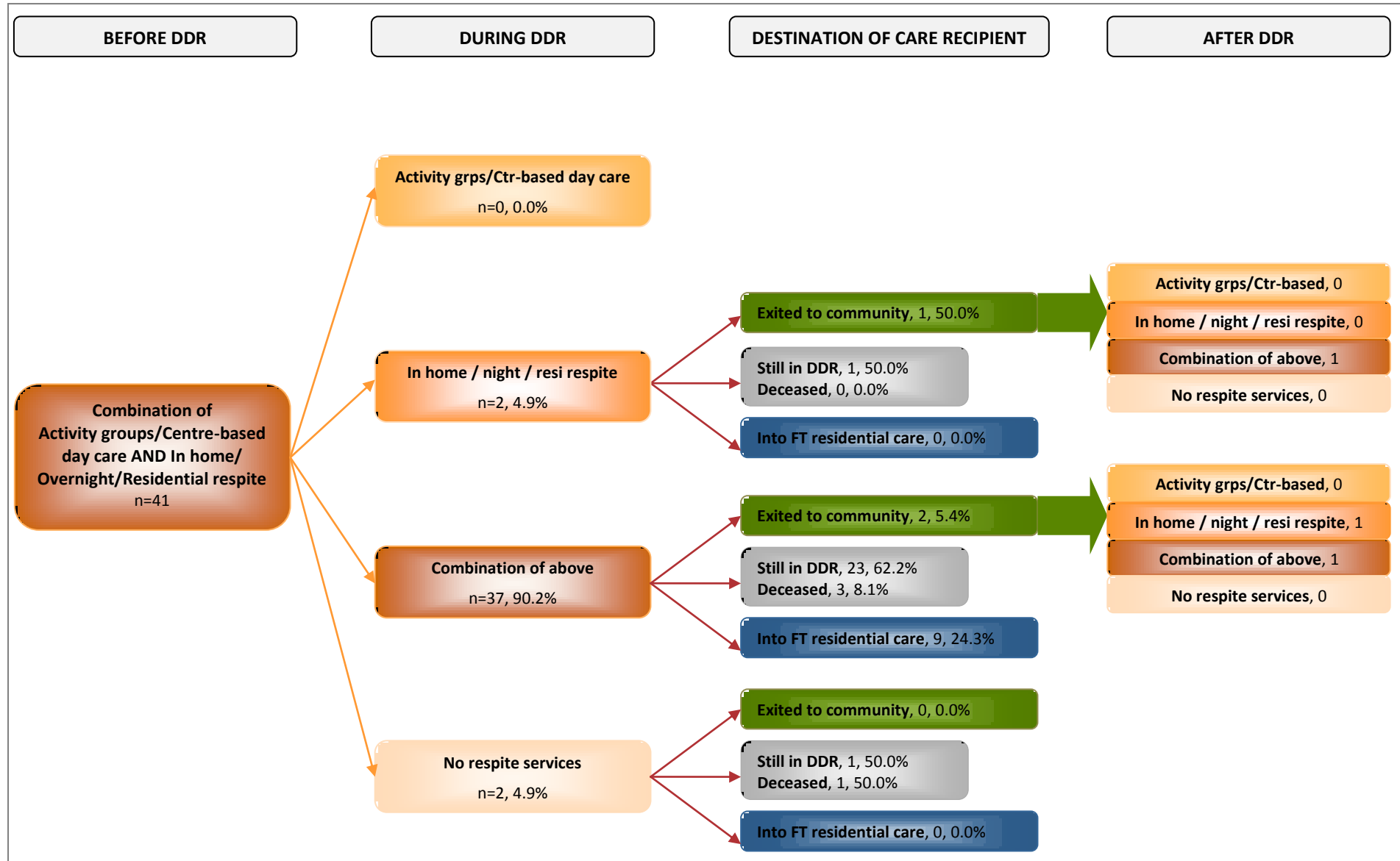
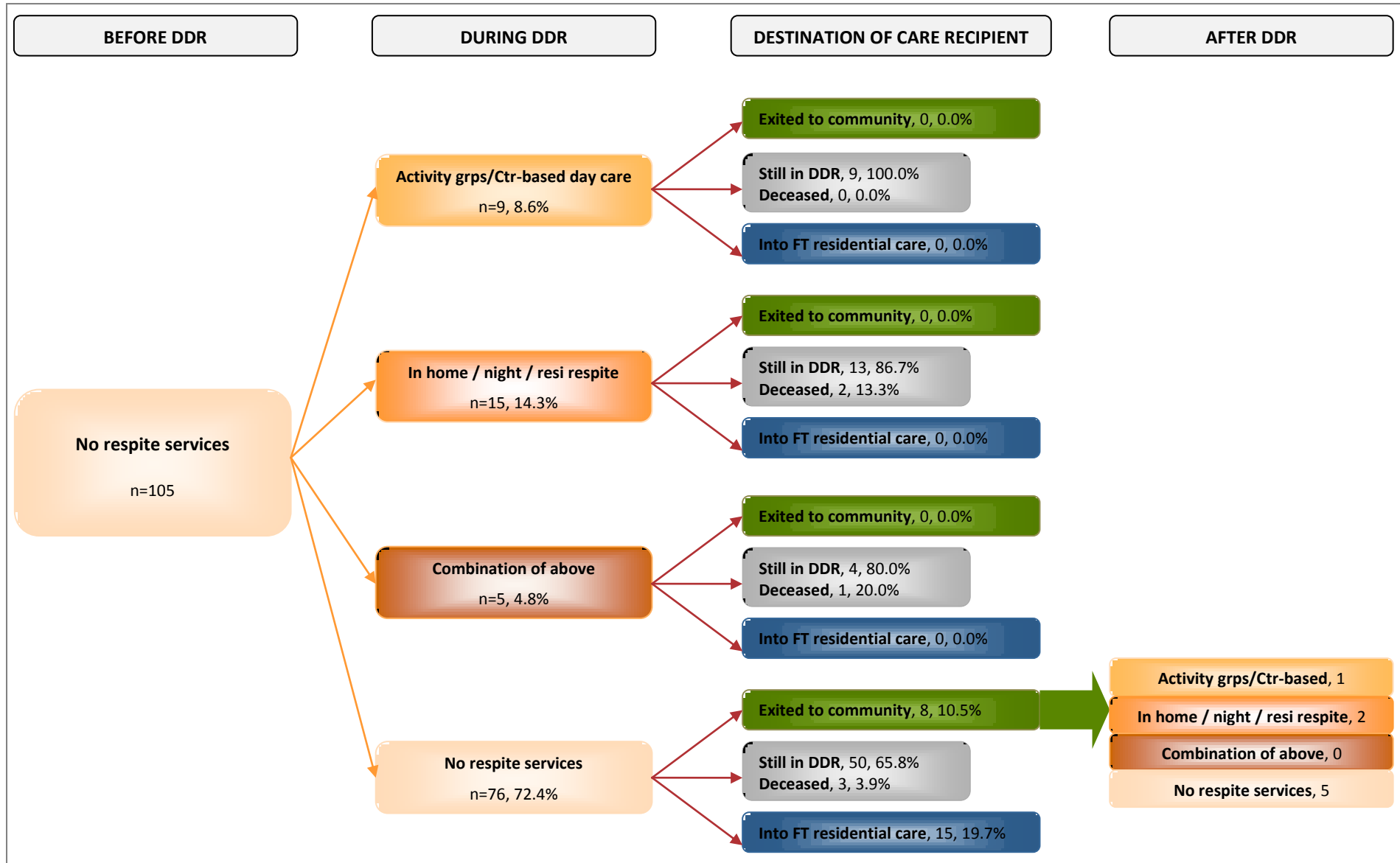


Figure 38: Respite service pathways for those who *did not use any respite services before entering the DDR service*



5 REFERENCES

- AIHW (2006) *The ins and outs of residential respite care*, Bulletin 43, July 2006, Australian Institute for Health and Welfare, Canberra
- AIHW (2009a) *Incorporating HACC use into aged care pathways: a technical report for the PIAC project*, Data Linkage Series #7, Australian Institute for Health and Welfare, Canberra (Cat CSI7)
- AIHW (2009b) *Pathways through aged care services: a first look*, Bulletin 73, October 2009, Australian Institute for Health and Welfare, Canberra
- AIHW (2010) *Dementia and the takeup of residential respite care*, Bulletin 78, April 2010, Australian Institute for Health and Welfare, Canberra
- AIHW (2011) *Pathways in Aged Care: program use after assessment*, Data linkage series no. 10. CSI 10, Australian Institute for Health and Welfare, Canberra
- Holm, S (1979) A simple sequential rejective multiple test procedure, *Scandinavian Journal of Statistics*, 6:65-70

AUSTRALIAN INSTITUTE
FOR SOCIAL RESEARCH



EVALUATION OF THE DAY RESPITE IN RESIDENTIAL AGED CARE FACILITIES INITIATIVE

Client Pathway Survey

The *Australian Institute for Social Research* at The University of Adelaide is evaluating the *Day Respite in Residential Aged Care Facilities Initiative* for the Department of Health and Ageing. As part of this Evaluation we would like to **better understand the pathways that Carers take through the various services offered to them.**

Purpose of the survey

This survey seeks information on the types of programs and services that Carers use *before, during* and *after* their involvement with the Day Respite Service. This will help us to better understand the needs of Carers and how those needs change over time.

Who should complete this survey?

This survey is for **Carers who used the Day Respite Service at some time during 2010**, regardless of whether or not they are still using the service. If you are a Carer who stopped using the service due to your loved one passing away, we hope that you might still feel able to take part in this important survey.

Is the survey compulsory?

Participation in this survey is **voluntary**. However your input is very important. It will ensure that we obtain information about a range of people with different experiences.

Confidentiality

The information you give us will be treated as **confidential**. Results from this survey will be released in a way that does *not* allow individuals to be identified.

How to participate

 Complete this questionnaire within the next week or so – it will take about 15 minutes

 Return your completed questionnaire using the reply-paid envelope supplied (no stamp required)

Further information

If you would like any further information about this survey, please contact Naomi Guiver, Senior Research Fellow at the *Australian Institute for Social Research*, on (08) 8303 3391 or by email at naomi.guiver@adelaide.edu.au.

PART A: INTRODUCTION

1. Please indicate which of the following Day Respite Services you used in 2010:

NSW:

- Warnervale Wellness Centre's Day Respite Service (run by Catholic HealthCare)
- Constitution Hill Day Respite Centre (run by Australian Unity Retirement Living Services)
- Our Lady of Consolation Day Respite Service (run by Our Lady of Consolation Aged Care)
- Warrigal Community Care Day Respite Service (run by Warrigal Care)

VIC:

- The Caring Café (run by Inner East Community Health Service)
- Homestead Day Stay Respite (run by Lyndoch Warrnambool Inc)
- Manningham Centre Day Guest Respite Service (run by Manningham Centre Assoc Inc)

QLD:

- Garden City Retirement Home's Day Respite Service (run by Alzheimer's Assoc of Qld Inc)
- Spiritus Wide Bay (Kirami) Day Respite Service (run by Spiritus Care Services)

SA:

- Perry Park's Riverview Day Respite Service (run by ACH Group Inc)
- Ross Robertson Day Respite Service (run by ECH Inc)

WA:

- St Ives Day Respite Service (run by Aged Care Services Australia Inc, St Ives Group)
- Morrison Lodge Day Respite Service (run by City of Swan Aged Persons Trust Inc)

NT:

- Rocky Ridge Day Respite Service (run by Uniting Church Frontier Services)

The following questions refer to the Day Respite Service that you indicated above.

If more than one person in your care attended this Day Respite Service in 2010, please answer this questionnaire in respect of the person who spent the most amount of time at this Day Respite Service in 2010.

PART B: USING THE DAY RESPITE SERVICE

2. How did you **first become aware** of this Day Respite Service? *(Please tick as many as apply)*

- Through my GP
- Through another health professional
- Via an assessment for a Government package, program or service
- Through a Carer Information, Support or Linkage service
- Through another service that I was using
- Through advertising
- Through family or friends
- Other *(please specify)* _____

3. Were you initially placed on a **waiting list** for this Day Respite Service? *(Please tick one)*

- Yes
- No ⇒ *Please go to Question 5*

4. How long were you on the waiting list?

(Please tick one. If you are not sure, please give your best estimate.)

- Less than one week
- One to two weeks
- Three to four weeks
- Between one and three months
- Between three and six months
- More than six months

5. In total, how long were you **involved with** this Day Respite Service, from the first time that you used the service to the most recent time that you used the service?

(Please tick one. If you are not sure, please give your best estimate.)

- Less than one month
- Between one and three months
- Between three and six months
- Between six and twelve months
- Between one and two years
- More than two years

PART C: BEFORE USING THE DAY RESPITE SERVICE

Please think back to the time *before* you first used the Day Respite Service.

6. The table below shows the five main **Government packages and programs** available to help older people and their carers. These packages and programs provide access to broad range of different services. We are interested in which of these packages/programs, if any, that you and the person you care(d) for received assistance from *before* you started using the Day Respite Service.

Please fill in the table below by ticking “Yes” or “No” in each section. Tick “Don’t know” if you are unsure.

	<i>Used BEFORE you started using the Day Respite Service?</i>
<p>Home and Community Care (HACC) program The HACC program provides home- and community-based services for people requiring assistance because of disability and/or frailty, and for their carers.</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don’t know
<p>Veterans’ Home Care (VHC) program The VHC program is a Department of Veterans’ Affairs (DVA) program designed to assist veterans and war widows/widowers to continue living at home, by providing a small amount of practical help. It is similar to the HACC program.</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don’t know
<p>Community Aged Care Packages (CACPs) CACP packages are designed to assist older people with complex needs to live at home.</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don’t know
<p>Extended Aged Care at Home (EACH) packages EACH packages are flexible, individually planned packages of care, which help older people to live at home.</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don’t know
<p>Extended Aged Care at Home Dementia (EACHD) packages EACHD packages are flexible, individually planned packages of care, designed to help older people who experience difficulties associated with dementia.</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don’t know

7. You and the person you care(d) for may have used a range of different **types of services** to help you on a day-to-day basis. These services may or may not have been part of a government package/program. We are interested in which types of services that you and the person you care(d) for used *before* your involvement with the Day Respite Service.

Please fill in the table below by indicating with a tick (✓) whether you and/or the person you care(d) for used each type of service *before* your involvement with the Day Respite Service.

	<i>Used BEFORE you started using the Day Respite Service?</i>
Home help e.g. cleaning, washing and ironing, help with shopping and errands, help preparing meals and other day-to-day activities within the home	
Property maintenance e.g. help with maintaining and repairing the home, garden or yard, modifications to the home such as ramps and shower rails	
Food services e.g. Meals on Wheels or meals at a Centre	
Help with transport e.g. to get to appointments or to go on outings	
Personal care services e.g. help with bathing, dressing, grooming, eating, toileting, getting in and out of bed and moving about the house	
Nursing services e.g. health care delivered by nurses either at home, at a community venue or at a clinic	
Allied Health services e.g. physiotherapy, podiatry, occupational therapy, counselling	
Carer Information, Support or Linkage services	
Friendly visiting, Telelink or other general support services	
Activity groups (not part of this Day Respite Service) e.g. run by other Aged Care Facilities, Church groups, Senior Citizens Clubs	
Respite care provided <u>in my home</u> (daytime or overnight) i.e. "in-home respite"	
Other Centre-based Day Care i.e. Day Respite outside the home but NOT the particular Day Respite Service that this Survey pertains to	
Overnight respite care at an Aged Care Facility e.g. one-night stays at an aged care hostel or nursing home	
Residential respite care at an Aged Care Facility e.g. days or weeks at an aged care hostel or nursing home	

8. Before you started using the Day Respite Service, did you and the person you care(d) for use any other type of service to help them to remain living at home? (Please tick one)

- No
- Yes (Please list below)

Other services used *before* your involvement with the Day Respite Service

9. What additional services would have also been helpful at that time? (Please tick one)

- None – we had all the services we needed at that time
- Additional services would have been helpful (Please list below)

Additional services needed *before* becoming involved with the Day Respite Service

PART D: DURING THE TIME THAT YOU WERE/ARE INVOLVED WITH THE DAY RESPITE SERVICE

Please think about *the period of time in which you were/are using the Day Respite Service*.

10. While involved with the Day Respite Service, do/did you and the person you care(d) for still use the same **Government packages and programs**, if any, as you did *before* becoming involved with the Day Respite Service? (Please tick one)

- Yes, used/using the same Government packages/programs (i.e. the same as Q6)
- No, we do/did *not* use the same Government packages and programs ⇒ *Please fill in the table below to indicate which packages/programs were stopped and which were started.*

	While involved with the Day Respite Service (leave blank if no change)
Home and Community Care (HACC) program The HACC program provides home- and community-based services for people requiring assistance because of disability and/or frailty, and for their carers.	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Veterans' Home Care (VHC) program The VHC program is a Department of Veterans' Affairs (DVA) program designed to assist veterans and war widows/widowers to continue living at home, by providing a small amount of practical help. It is similar to the HACC program.	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Community Aged Care Packages (CACPs) CACP packages are designed to assist older people with complex needs to live at home.	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Extended Aged Care at Home (EACH) packages EACH packages are flexible, individually planned packages of care, which help older people to live at home.	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Extended Aged Care at Home Dementia (EACHD) packages EACHD packages are flexible, individually planned packages of care, designed to help older people who experience difficulties associated with dementia.	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using

11. While involved with the Day Respite Service, do/did you and the person you care for use the same **types of services** as you did before? (Please tick one)

- Yes, we are/were using all of the same types of services (i.e. the same as Q7)
- No, we do/did *not* use all of the same types of services ⇒ Please fill in the table below to indicate which types of service were stopped and which were started.

	While involved with the Day Respite Service (leave blank if no change)
Home help e.g. cleaning, washing and ironing, help with shopping and errands, help preparing meals and other day-to-day activities within the home	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Property maintenance e.g. help with maintaining and repairing the home, garden or yard, modifications to the home such as ramps and shower rails	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Food services e.g. Meals on Wheels or meals at a Centre	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Help with transport e.g. to get to appointments or to go on outings	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Personal care services e.g. help with bathing, dressing, grooming, eating, toileting, getting in and out of bed and moving about the house	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Nursing services e.g. health care delivered by nurses either at home, at a community venue or at a clinic	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Allied Health services e.g. physiotherapy, podiatry, occupational therapy, counselling	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Carer Information, Support or Linkage services	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Friendly visiting, Telelink or other general support services	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Activity groups (not part of this Day Respite Service) e.g. run by other Aged Care Facilities, Church groups, Senior Citizens Clubs, etc	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Respite care provided <u>in my home</u> (daytime or overnight) i.e. "in-home respite"	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Other Centre-based Day Care i.e. Day Respite outside the home but NOT the particular Day Respite Service that this Survey pertains to	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Overnight respite care at an Aged Care Facility e.g. one-night stays at an aged care hostel or nursing home	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using
Residential respite care at an Aged Care Facility e.g. days or weeks at an aged care hostel or nursing home	<input type="checkbox"/> Stopped using <input type="checkbox"/> Started using

12. While involved with the Day Respite Service, do/did you and the person you care(d) for use any other type of service to help them to remain living at home? (Please tick one)

- No
- Yes (Please list below)

Other services used during your involvement with the Day Respite Service

13. What additional services would have been helpful while you were involved with the Day Respite Service? (Please tick one)

- None – we have/had all the services we need
- Additional services would be helpful (Please list below)

Additional services that would be helpful while involved with the Day Respite Service

14. Are you still using the Day Respite Service? (Please tick one)

- Yes ⇒ Please go to Question 21 (page 13)
- No, I have finished using the Day Respite Service ⇒ Please continue over page

PART E: AFTER USING THE DAY RESPITE SERVICE

15. How long ago did you stop using the Day Respite Service? (Please tick one)

- Less than one month ago
- Between one and three months ago
- Between three and six months ago
- Between six and twelve months ago
- More than twelve months ago

16. What are the reasons that you stopped using the Day Respite Service? (Tick all that apply)

- The person in my care entered *low level* full time residential care (i.e. a hostel)
- The person in my care entered *high level* full time residential care (i.e. a nursing home)
- The person in my care passed away
- The person in my care became too physically unwell to continue using the service
- The person had behavioural issues that could no longer be managed by the service
- We moved away from the area
- We had difficulty getting transport to/from the Day Respite Service
- We could not afford the cost of the service
- The person in my care did not wish to continue using the service
- I was dissatisfied with the service
- I found other day respite service(s) that were more appropriate to our needs
- I found other types of service(s) that were more appropriate to our needs
- Other reasons (please specify below)

Other reasons

17. What **Government packages and programs**, if any, are you and the person you care(d) for **currently using**?
Please fill in the table below by ticking “Yes” or “No” in each section; tick “Don’t know” if you are unsure.

	Used CURRENTLY?
<p>Home and Community Care (HACC) program The HACC program provides home- and community-based services for people requiring assistance because of disability and/or frailty, and for their carers.</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don’t know
<p>Veterans’ Home Care (VHC) program The VHC program is a Department of Veterans’ Affairs (DVA) program designed to assist veterans and war widows/widowers to continue living at home, by providing a small amount of practical help. It is similar to the HACC program.</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don’t know
<p>Community Aged Care Packages (CACPs) CACP packages are designed to assist older people with complex needs to live at home.</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don’t know
<p>Extended Aged Care at Home (EACH) packages EACH packages are flexible, individually planned packages of care, which help older people to live at home.</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don’t know
<p>Extended Aged Care at Home Dementia (EACHD) packages EACHD packages are flexible, individually planned packages of care, designed to help older people who experience difficulties associated with dementia.</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don’t know

18. What types of services, if any, are you and the person you care(d) for *currently using*?

Please fill in the table below by indicating with a tick (✓) which services are currently being used.

	<i>Used CURRENTLY?</i>
Home help e.g. cleaning, washing and ironing, help with shopping and errands, help preparing meals and other day-to-day activities within the home	
Property maintenance e.g. help with maintaining and repairing the home, garden or yard, modifications to the home such as ramps and shower rails	
Food services e.g. Meals on Wheels or meals at a Centre	
Help with transport e.g. to get to appointments or to go on outings	
Personal care services e.g. help with bathing, dressing, grooming, eating, toileting, getting in and out of bed and moving about the house	
Nursing services e.g. health care delivered by nurses either at home, at a community venue or at a clinic	
Allied Health services e.g. physiotherapy, podiatry, occupational therapy, counselling	
Carer Information, Support or Linkage services	
Friendly visiting, Telelink or other general support services	
Activity groups (not part of this Day Respite Service) e.g. run by other Aged Care Facilities, Church groups, Senior Citizens Clubs	
Respite care provided <u>in my home</u> (daytime or overnight) i.e. "in-home respite"	
Other Centre-based Day Care i.e. Day Respite outside the home but NOT the particular Day Respite Service that this Survey pertains to	
Overnight respite care at an Aged Care Facility e.g. one-night stays at an aged care hostel or nursing home	
Residential respite care at an Aged Care Facility e.g. days or weeks at an aged care hostel or nursing home	
Full time residential care – <i>low level</i> (i.e. hostel)	
Full time residential care – <i>high level</i> (i.e. nursing home)	
Ongoing hospital or hospice care	

19. Since leaving the Day Respite Service, have you and the person you care(d) for used any other type of service to help either of you to remain living at home? *(Please tick one)*

- No
- Yes *(Please list below)*

Other services being used now

20. What additional services would be helpful now? *(Please tick one)*

- None – we have all the services we need
- Additional services would be helpful *(Please list below)*

Additional services that would be helpful now

PART F: ABOUT YOU AND THE PERSON YOU PROVIDE(D) CARE FOR

21. We would like to understand how different types of services suit different groups of people. **Please fill in the table below** by providing information about *you* in the middle column of the table, and information about *the person that you provide(d) care for* in the right hand column.

	You	The person that you provide(d) care for
Age (in years)	<input type="text"/> <input type="text"/> <input type="text"/> Years	<input type="text"/> <input type="text"/> <input type="text"/> Years
Sex (Please tick one)	<input type="checkbox"/> Male <input type="checkbox"/> Female	<input type="checkbox"/> Male <input type="checkbox"/> Female
Marital status (Tick one)	<input type="checkbox"/> Married/Defacto <input type="checkbox"/> Widowed <input type="checkbox"/> Divorced <input type="checkbox"/> Separated but not divorced <input type="checkbox"/> Never married	<input type="checkbox"/> Married/Defacto <input type="checkbox"/> Widowed <input type="checkbox"/> Divorced <input type="checkbox"/> Separated but not divorced <input type="checkbox"/> Never married
Of Aboriginal or Torres Strait Islander origin? (Tick one)	<input type="checkbox"/> No <input type="checkbox"/> Yes, Aboriginal or Torres Strait Islander	<input type="checkbox"/> No <input type="checkbox"/> Yes, Aboriginal or Torres Strait Islander
Country of birth	<input type="checkbox"/> Australia <input type="checkbox"/> Other country (please specify) _____	<input type="checkbox"/> Australia <input type="checkbox"/> Other country (please specify) _____
Main language spoken <u>at home</u>	<input type="checkbox"/> English <input type="checkbox"/> Other language (please specify) _____	<input type="checkbox"/> English <input type="checkbox"/> Other language (please specify) _____
Postcode	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

22. While involved with the Day Respite Service, do/did you **live with** the person you provide(d) care for? (Please tick one)

- Yes – all or most of the time
- Yes – some of the time
- No

23. What is your relationship to the person you provide(d) care for? (Please tick one)

- Caring for my spouse or partner
- Caring for my parent, parent-in-law or step-parent
- Caring for another relative (e.g. grandparent, aunt/uncle, brother/sister, child)
- Caring for a friend or neighbour
- Other (please specify) _____

24. Which of the following conditions do/did the person in your care have while they were attending the Day Respite Service? (Please tick as many as apply)

- Unwell/in poor health
- Terminal illness (e.g. due to cancer)
- Frailty, mobility problems
- Dementia/memory loss issues
- Behaviours that are difficult to manage
- Psychological problems (e.g. depression, severe anxiety)
- Other (please specify) _____

25. How would you describe your own physical health at present? (Please tick one)

- Very good
- Good
- Fair
- Poor
- Very poor

26. How would you describe your own emotional and mental wellbeing at present? (Tick one)

- Very good
- Good
- Fair
- Poor
- Very poor

Thank you for taking the time to complete this survey. We appreciate your help.

If you have mislaid the reply-paid envelope, the Reply Paid address (no stamp required) is:

Client Pathways Survey
Australian Institute for Social Research (68)
The University of Adelaide
Reply Paid 498
ADELAIDE SA 5001