PR0278 - Families Caring for a Person with a Disability Questionnaire for Main Study V1
(incorporating changes resulting from pilot test 3 (5th October))

Module structure

<table>
<thead>
<tr>
<th>SRC module</th>
<th>Description</th>
<th>AIFS module</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Disabling condition and caring role</td>
<td>A</td>
</tr>
<tr>
<td>B</td>
<td>Care of person with disability</td>
<td>B</td>
</tr>
<tr>
<td>C</td>
<td>Household composition and demographic characteristics</td>
<td>C</td>
</tr>
<tr>
<td>D</td>
<td>Service use</td>
<td>L</td>
</tr>
<tr>
<td>E</td>
<td>Support networks</td>
<td>E</td>
</tr>
<tr>
<td>F</td>
<td>Family life events</td>
<td>F</td>
</tr>
<tr>
<td>G</td>
<td>Family relationships</td>
<td>G</td>
</tr>
<tr>
<td>H</td>
<td>Caregiver’s general health and wellbeing</td>
<td>D</td>
</tr>
<tr>
<td>I</td>
<td>About your social life</td>
<td>K</td>
</tr>
<tr>
<td>J</td>
<td>About education</td>
<td>H</td>
</tr>
<tr>
<td>K</td>
<td>About work</td>
<td>I</td>
</tr>
<tr>
<td>L</td>
<td>Financial issues</td>
<td>J</td>
</tr>
</tbody>
</table>

Introduction and consents

Intro1 Good (…), my name is (…) calling on behalf of the Australian Institute of Family Studies from the Social Research Centre. Can I speak to <named carer from sample>?

IF ASKED: I am calling to follow up a brochure that was sent to you / <named carer from sample> about the “The Families Caring for a Person with a Disability Study”.

IF NECESSARY: The brochure is blue with brightly coloured shapes…

1. Continue

REINTRODUCE AS NECESSARY

Good (…), my name is (…) calling on behalf of the Australian Institute of Family Studies from the Social Research Centre.

IF ASKED: I am calling to follow up a brochure that was sent to you about the “The Families Caring for a Person with a Disability Study”.

IF NECESSARY: The brochure is blue with brightly coloured shapes…

1. Continue
2. Wants a copy of the brochure before proceeding (GO TO ALET)
3. Stop interview, make appointment (RECORD NAME AND ARRANGE CALL BACK)
4. Household refusal (ATTEMPT CONVERSION / RECORD REASON) (GO TO RR1)
5. Respondent refusal (ATTEMPT CONVERSION / RECORD REASON) (GO TO RR1)
6. HH LOTE – (Vietnamese, Arabic, Cantonese, Mandarin, Italian, Greek) follow up (GO TO ALOTE)
7. HH LOTE – Other language identified (no language follow up) (GO TO ALOTE)
8. HH LOTE – Language not identified (make appointment) (RECORD ON SMS)
9. Queried about how telephone number was obtained (DISPLAY ATELQ)
10. Respondent not known (SMS SCREEN)
The Social Research Centre

*(NAMED SAMPLE MEMBER)

Intro2  WHEN TALKING TO NAMED PERSON

As the brochure says, the study aims to get a better understanding of how families care for a person with a disability and how it affects family life.

This interview should take approximately 25 minutes of your time, but may vary depending on your circumstances. Is now a good time to talk?

IF NECESSARY: If you need to stop at any time during the interview, we can arrange to finish off at a time convenient to you

1. Start survey (GO TO S1)
2. Wants a copy of the brochure before proceeding (GO TO ALET)
3. Stop interview, make appointment (RECORD NAME AND ARRANGE CALL BACK)
4. Household refusal (ATTEMPT CONVERSION / RECORD REASON) (GO TO RR1)
5. Respondent refusal (ATTEMPT CONVERSION / RECORD REASON) (GO TO RR1)
6. QR LOTE – (Vietnamese, Arabic, Cantonese, Mandarin, Italian, Greek) follow up (GO TO ALOTE)
7. QR LOTE – Other language identified (no language follow up) (GO TO ALOTE)
8. QR LOTE – Language not identified (make appointment) (RECORD ON SMS)
9. Queried about how telephone number was obtained (DISPLAY ATELQ)

*(WANTS TO RECEIVE A COPY OF THE BROCHURE)

ALET  Record address details to send copy of brochure

(RECORD NAME AND VERIFY ADDRESS DETAILS FROM SAMPLE / COLLECT ADDRESS DETAILS)

*(LOTES)

ALOTE Record language

1. Arabic
2. Vietnamese
3. Mandarin
4. Cantonese
5. Italian
6. Greek
7. Other (specify) (RECORD ON SMS)

*(QUERIED HOW TELEPHONE NUMBER WAS OBTAINED)

ATELQ Your family was selected as part of a large sample randomly chosen from Centrelink records of families with caring responsibilities.

1. Snap back to Intro1 / Intro2

S1  Just to confirm you are one of the people we need to talk to….

Are you receiving a carer allowance and / or carer payment?

1. Yes
2. No (GO TO TERMINATION SCRIPT 1)

*(ALL)

Intro3  Couple of things I wanted to mention before we get started:

Firstly, all information collected in this study will be kept strictly confidential as required by the Privacy Act. Personal details that could identify you or your family will not be provided to any government agency or the Australian Institute of Family Studies, and the information you provide will not impact on any government payments you may be receiving.

1. Continue
Secondly, this call may be monitored by my supervisor for quality assurance purposes. Please tell me if you don’t want this to happen.

1. Monitoring allowed
2. Monitoring not permitted
**A. Disabling condition and caring role**

*(ALL) (AIFS – PDNUM)*  
A2  To start then….. how many people who are aged or have a long-term illness or disability do you have a caring responsibility for?  

IF NECESSARY: This includes persons for whom you receive no carer payment through Centrelink  

By long-term we mean lasted or is likely to last for 6 months or more.  

1. One  
2. Two  
3. Three or more  
4. (Refused) (GO TO TERMINATION SCRIPT 2)

*PROGRAMMER NOTE: ASK A3 TO A13b FOR EACH PERSON (UP TO THREE) CARED FOR. TAILOR TEXT IN A3 INTRO B FOR (first / second / third) PERSON.

PREA3 IF A2=1 (CARES FOR ONE PERSON ONLY) GO TO A3 INTRO A. OTHERS GO TO A3 INTRO B

*(ALL) (AIFS – PDNAME)*  
A3 INTRO A What is that person’s name?  
INTRO B Starting with the first person – what is their name?  

IF NECESSARY: We only ask you this to help keep track of who we are talking about and to refer to this person by name throughout this interview  

1. Name given (specify)  
2. (Refused)

*PROGRAMMER NOTE: CONVENTION USED THROUGHOUT THIS QUESTIONNAIRE WHEN FEEDING FORWARD NAME OF PERSON WITH A DISABILITY IS <insert name from A3_1> FOR FIRST PERSON, <insert name from A3_2> FOR SECOND PERSON, ETC

*(ALL) (AIFS – PDREL)*  
A4 How is <insert name from A3> related to you?  

*PROGRAMMER NOTE: PRESENT AS DOUBLE COLUMN  

1. Husband / wife  
2. Partner/de facto  
3. Son / daughter  
4. Step-son / daughter  
5. Partner’s son / daughter  
6. Parent (including step parent)  
7. Parent-in-law  
8. Grandparent  
9. Grand child  
10. Brother / sister  
11. Uncle / aunt  
12. Friend  
13. Flatmate/Boarder  
14. Nanny/babysitter  
15. Other family (specify)  
16. Other (specify)  
17. (Don’t know)  
18. (Refused)
PREAa IF A4=1 (RESPONDENT'S HUSBAND OR WIFE) GO TO A4a INTRO A
   IF A4=2 (RESPONDENT'S PARTNER / DE FACTO) GO TO A4a INTRO B
   OTHERS GO TO A5

*(PERSON IS RESPONDENT'S PARTNER) (AIFS DEFACTO OR MARRIED)
A4a INTRO A In which year did you get married?
   INTRO B In which year did you start living with <insert name from A4>?

   IF NECESSARY: We’re asking these questions to try and build up a picture of the sequence
   of events around your caring responsibilities, for example, when you partnered, and whether
   that was before or after you started your caring responsibilities

   1. Year given (specify)
   2. (Don’t know year)
   3. (Refused)

*(ALL) (AIFS – PDAGE)
A5 How old is <insert name from A3>?

   1. Age given (specify) (ALLOWABLE RANGE 0-110)
   2. (Don’t know)
   3. (Refused)

*(ALL) (AIFS – PDSEX)
A6 Is <insert name from A3> male or female?

   1. Male
   2. Female
   3. (Refused)

*(ALL) (AIFS – PDIND)
A7 Does <insert name from A3> identify as Aboriginal or Torres Strait Islander?

   1. Yes
   2. No
   3. (Don’t know)
   4. (Refused)

*(ALL) (AIFS – PDLIV)
A8 Does <insert name from A3> live in the same household as you? CLARIFY AS NECESSARY

   1. Yes, always
   2. Yes, some of the time
   3. No
   4. (Don’t know)
   5. (Refused)

*(ALL) (AIFS – PDYR)
A9y In which year did you start providing care for <insert name from A3>?

   1. 2006
   2. Year given (specify) (RANGE: 2006 LESS AGE GIVEN IN A5 TO 2005) (GO TO A10)
   3. (Don’t know year) (GO TO A10)
   4. (Refused) (GO TO A10)
A9m  In which month did you start providing care for <insert name from A3>?

1. January
2. February
3. March
4. April
5. May
6. June
7. July
8. August
9. September
10. October
11. (Don’t know month)
12. (Refused)

*(ALL) (AIFS – PDHRS)

A10  In a TYPICAL week, how many hours would you provide care for <insert name from A3>?

INTERVIEWER NOTE: If respondent says “It varies” PROBE with “On average how many hours would you provide care for…” NOTE: If respondents says “all the time / full time” please probe with “Does that mean 24 hours, 7 days a week?” if so then use code 4, otherwise try to estimate the number of hours

1. Hours given (Specify__) (RANGE 1.0 TO 168.0)
2. All the time / 24*7
3. (Don’t know)
4. (Refused)

*(ALL) (AIFS – MED)

A13  What is <insert name from A3>’s PRIMARY medical diagnosis or disability? (IF NECESSARY: That is, the primary medical condition that is the cause of <insert name from A3>’s functional impairment.

INTERVIEWER NOTE: Do NOT force respondents to nominate one condition

*PROGRAMMER NOTE: Display list in 2 columns, 1st column codes 1-13 and column 2 codes 14-19

1. Multiple medical conditions
2. Osteoarthritis
3. Rheumatoid arthritis
4. Coronary artery disease
5. Major depression
6. Intellectual disability
7. Anxiety
8. Paralysis (hemiplegia)
9. Alzheimer's disease
10. Senile dementia
11. Schizophrenia
12. Blindness
13. Fractures and crush injuries
14. Cancer (Specify______) (e.g. lung, breast, prostate, bowel, brain, leukaemia)
15. Attention deficit/hyperactivity disorder
16. Learning disability
17. Autism
18. Asthma
19. Asperger’s disorder
20. Downes syndrome
21. Other (Specify________)
22. (Don’t know)
23. (Refused)
PREA13b IF A13=21 (MULTIPLES MEDICAL CONDITIONS) CONTINUE, OTHERS GO TO PREA14
*(MULTIPLE MEDICAL CONDITIONS)
A13b What medical conditions does <insert name from A3> have?
(ACCEPT MULTIPLES)

USE LIST FROM A13 (EXCLUDING CODE 1 – Multiple medical conditions)

*PROGRAMMER – CREATE NET MEDICAL CONDITIONS VARIABLE FOR EACH PWD FROM A13 / A13b IN OUTPUTS

PREA14 (CLOSE LOOP)

*(ALL)
A14 Do you have other caring responsibilities apart from providing care for....
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?

IF NECESSARY: By caring, we mean caring in a broader sense, not just caring for someone with a disability

MULTIPLES ACCEPTED

1. Yes – children (includes own / adopted / foster children)
2. Yes – parents / parents in law
3. Yes – other relative
4. Yes – other person
5. No
6. (Don’t know)
7. (Refused)
**B. Care of the person with the disability**

*ASK Bintro TO B12 FOR EACH PERSON WITH A DISABILITY FROM A3 (LOOP UP TO THREE TIMES)*

*(ALL)*

Bintro I now have some questions about times that <insert name from A3> may need somebody to help or look after them because of the condition(s) you have told me about....

1. Continue

PREB1 IF A5=7 OR MORE (PERSON WITH DISABILITY IS AGED 7 OR MORE) CONTINUE. OTHERS GO TO PREB4

*(PERSON WITH DISABILITY IS AGED 7 OR MORE) (AIFS DISA18)*

B1 Does <insert name from A3> ever need someone to help with, or be with them for, self care activities?

For example: doing everyday activities such as eating, showering, dressing or toileting.

INTERVIEWER NOTE: If respondent says “most” code as “always”

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)

*(PERSON WITH DISABILITY IS AGED 7 OR MORE) (AIFS – DISA19)*

B2 Does <insert name from A3> ever need someone to help with, or be with them for, body movement activities?

For example: getting out of bed, moving around at home or at places away from home.

INTERVIEWER NOTE: If respondent says “most” code as “always”

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)

*(PERSON WITH DISABILITY IS AGED 7 OR MORE) (AIFS – DISA20)*

B3 Does <insert name from A3> ever need someone to help with, or be with them for, communication activities?

For example: understanding, or being understood by, others.

INTERVIEWER NOTE: If respondent says “most” code as “always”

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)
*(PERSON WITH DISABILITY IS AGED 15 OR MORE) (AIFS – DISA21)
B4 Does <insert name from A3> ever need someone to help with making friendships, interacting with others or maintaining relationships?

INTERVIEWER NOTE: If respondent says “most” code as “always”

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)

*(PERSON WITH DISABILITY IS AGED 15 OR MORE) (AIFS – DISA22)
B5 Does <insert name from A3> ever need someone to help with coping with feelings or emotions?

INTERVIEWER NOTE: If respondent says “most” code as “always”

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)

*(PERSON WITH DISABILITY IS AGED 15 OR MORE) (AIFS – DISA23)
B6 Does <insert name from A3> ever need someone to help with making decisions or thinking through problems?

INTERVIEWER NOTE: If respondent says “most” code as “always”

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)

PREB7 IF A5=6 OR UNDER (PERSON WITH A DISABILITY IS AGED 6 OR LESS) CONTINUE. OTHERS GO TO PREB10)

*(PERSON WITH A DISABILITY IS AGED 6 OR LESS) (AIFS – DISB18)
B7 Does <insert name from A3> ever need more care or help than other children (his / her) own age for self care activities?

For example: doing everyday activities such as eating, showering, dressing or toileting.

INTERVIEWER NOTE: If respondent says “most” code as “always”

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)
B8 Does <insert name from A3> ever need more care or help than other children (his / her) own age for body movement activities?

For example: getting out of bed, moving around at home or at places away from home.

INTERVIEWER NOTE: If respondent says “most” code as “always”

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)

B9 Does <insert name from A3> ever need more care or help than other children (his / her) own age for communication activities?

For example: understanding, or being understood by, others.

INTERVIEWER NOTE: If respondent says “most” code as “always”

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)

PREB10 IF A5=14 OR UNDER (CARING FOR PERSON AGED 14 OR LESS) CONTINUE. OTHERS GO TO Cintro

B10 Does <insert name from A3> ever need more care or help than other children (his / her) own age to interact or play with others?

INTERVIEWER NOTE: If respondent says “most” code as “always”

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)

B11 Does <insert name from A3> ever need more care or help than other children (his / her) own age to cope with feelings or emotions?

INTERVIEWER NOTE: If respondent says “most” code as “always”

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)
*(PERSON WITH A DISABILITY AGED 14 OR LESS) (AIFS – DISB23)

B12 Does <insert name from A3> ever need more care or help than other children his/her own age to manage his/her behaviour?

INTERVIEWER NOTE: If respondent says "most" code as "always"

1. Yes, always
2. Yes, sometimes
3. No
4. (Don’t know)
5. (Refused)

*(CLOSE LOOP)
C. Household composition and demographic characteristics

*ALL* In the next series of questions, I’d like to start building up a picture of the support you receive in your carer duties, whether from other people in your household, other family members, other individuals or other support services.

I’d like to start by asking some questions about you and the other members of your household….

1. Continue

*ALL (AIFS – CAGE)*
C1 Firstly, how old are you?

1. Age given (Specify____) (RANGE 15-110)
2. (Refused)

*ALL (AIFS – CSEX)*
C2 RECORD RESPONDENT GENDER.

1. Male
2. Female

*ALL (AIFS – CIND)*
C3 Do you identify as Aboriginal or Torres Strait Islander?

1. Yes
2. No
3. (Don’t know)
4. (Refused)

*ALL (AIFS – RELNUM)*
C4 APART from…

Yourself

<insert name from A3_1> DISPLAY IF A8_1=1 OR 2 (FIRST PERSON WITH A DISABILITY LIVES IN HOUSEHOLD)

<insert name from A3_2> DISPLAY IF A8_2=1 OR 2 (SECOND PERSON WITH A DISABILITY LIVES IN HOUSEHOLD)

<insert name from A3_3> DISPLAY IF A8_3=1 OR 2 (THIRD PERSON WITH A DISABILITY LIVES IN HOUSEHOLD)

…. how many other people, including any children, currently live in your household?

IF NECESSARY: By “currently live”, we mean stays in your household at least 4 nights each week or 7 nights each fortnight.

1. One
2. Two
3. Three
4. Four
5. Five
6. Six
7. Seven
8. Eight or more
9. No other household members (GO TO D1)
10. (Refused) (GO TO D1)
*PROGRAMMER NOTE: ASK C5 TO C10c FOR EACH OTHER PERSON (UP TO EIGHT) IN THE HOUSEHOLD. TAILOR TEXT IN C5 INTRO B FOR (first / second / third, etc) PERSON.

PREC5 IF C4=1 (ONE OTHER PERSON IN HOUSEHOLD ONLY) GO TO C5 INTRO A. OTHERS GO TO C5 INTRO B

*(OTHER PERSONS IN HOUSEHOLD) (AIFS – RELNAME)
C5 INTRO A What is that person’s name?
INTRO B Starting with the first person – what is their name?

IF NECESSARY: We only ask you this to help keep track of who we are talking about and to help get a clear picture of who is in the household and how they are related to each other

1. Name given (Specify___)
2. (Refused)

*(OTHER PERSONS IN HOUSEHOLD) (AIFS – AGE)
C6 And how old is <insert name from C5>?

1. Age given (Specify____) (RANGE 0 TO 110)
2. (Don’t know)
3. (Refused)

*(OTHER PERSONS IN HOUSEHOLD) (AIFS – SEX)
C7 RECORD GENDER OF <insert name from C5>?

1. Male
2. Female
3. (Refused)

*(OTHER PERSONS IN HOUSEHOLD) (AIFS – RELCARE)
C8 And how is <insert name from C5> related to you?

*PROGRAMMER NOTE: PRESENT AS DOUBLE COLUMN

1. Husband / wife
2. Partner/de facto
3. Son / daughter
4. Step-son / daughter
5. Partner's son / daughter
6. Parent (including step parent)
7. Parent-in-law
8. Grandparent
9. Grand child
10. Brother / sister
11. Uncle / aunt
12. Friend
13. Flatmate/Boarder
14. Nanny/babysitter
15. Other family (specify)
16. Other (specify)
17. (Don’t know)
18. (Refused)
PREC9 IF C8=1 (RESPONDENT'S HUSBAND OR WIFE) GO TO C9 INTRO A
IF C8=2 (RESPONDENT'S PARTNER / DE FACTO) GO TO C9 INTRO B
OTHERS GO TO C10a

*(PERSON IS RESPONDENT'S PARTNER) (AIFS DEFACTO OR MARRIED)
C9
INTRO A  In which year did you get married?
INTRO B  In which year did you start living with <insert name from c5>?

IF NECESSARY: We're asking these questions to try and build up a picture of the sequence of events around your caring responsibilities, for example, when you partnered, and whether that was before or after you started your caring responsibilities

1. Year given (specify) (RANGE: 2006 LESS AGE GIVEN IN C1 TO 2006+ 15 YEARS)
2. (Don't know year)
3. (Refused)

*(OTHER PERSONS IN HOUSEHOLD) (AIFS – RELPWD)
C10a  (Just to confirm) What is <insert name from C5>’s relationship to <insert name from A3_1>?

*PROGRAMMER NOTE: PRESENT AS DOUBLE COLUMN

1. Husband / wife
2. Partner/de facto
3. Son / daughter
4. Step-son / daughter
5. Partner's son / daughter
6. Parent (including step parent)
7. Parent-in-law
8. Grandparent
9. Grand child
10. Brother / sister
11. Uncle / aunt
12. Friend
13. Flatmate/Boarder
14. Nanny/babysitter
15. Other family (specify)
16. Other (specify)
17. (Don't know)
18. (Refused)
*(OTHER PERSONS IN HOUSEHOLD / SECOND PERSON WITH DISABILITY) (AIFS RELPWD)
C10b  (Just to confirm) And what is <insert name from C5>’s relationship to <insert name from A3_2>

*PROGRAMMER NOTE: PRESENT AS DOUBLE COLUMN

1. Husband / wife
2. Partner/de facto
3. Son / daughter
4. Step-son / daughter
5. Partner's son / daughter
6. Parent (including step parent)
7. Parent-in-law
8. Grandparent
9. Grand child
10. Brother / sister
11. Uncle / aunt
12. Friend
13. Flatmate/Boarder
14. Nanny/babysitter
15. Other family (specify)
16. Other (specify)
17. (Don't know)
18. (Refused)

PREC10c  IF THIRD PERSON WITH DISABILITY FROM A3, CONTINUE, ELSE GO TO DUM1

*(OTHER PERSONS IN HOUSEHOLD / THIRD PERSON WITH DISABILITY) (AIFS RELPWD)
C10c  (Just to confirm) And what is <insert name from C5>’s relationship to <insert name from A3_3>

*PROGRAMMER NOTE: PRESENT AS DOUBLE COLUMN

1. Husband / wife
2. Partner/de facto
3. Son / daughter
4. Step-son / daughter
5. Partner's son / daughter
6. Parent (including step parent)
7. Parent-in-law
8. Grandparent
9. Grand child
10. Brother / sister
11. Uncle / aunt
12. Friend
13. Flatmate/Boarder
14. Nanny/babysitter
15. Other family (specify)
16. Other (specify)
17. (Don't know)
18. (Refused)

* (CLOSE LOOP)

DUM1 PARTNER IN HOUSEHOLD
*CREATE DUMMY VARIABLE FOR PARTNER IN HOUSEHOLD

1. Yes (IF (A4=CODES 1 OR 2 AND A8=CODES 1 OR 2) OR (C8=CODES 1 OR 2))
2. No (ALL OTHERS)
DUM2 CHILDREN IN HOUSEHOLD EXCLUDING PWD
*CREATE DUMMY VARIABLE FOR CHILDREN IN HOUSEHOLD

1. Yes – one child in household (IF C8=CODES 3-5 OR 9 SINGLE CODED ONLY)
2. Yes – two or more children in household (IF C8=CODES 3-5 OR 9 MULTI CODED)
3. No (ALL OTHERS)
**D. Service use**

*PROGRAMMER INSTRUCTION: IF (MULTIPLE PERSON HOUSEHOLD) INCLUDE <or anyone else in your household> IN QUESTION STEM

*(ALL) (AIFS – SERV1 TO SERV6)

**D1** Could you please tell me whether you, or <insert name from A3_1> <insert name from A3_2> <insert name from A3_3> (or anyone else in your household) uses any disability services like respite, counselling, disability employment services or carer support services. (IF YES, PROBE TO CLARIFY) (ACCEPT MULTIPLES) (REFER TO LOOK UP SHEET FOR EXPLANATIONS OF SOME SERVICES)

*PROGRAMMER NOTE: PRESENT AS DOUBLE COLUMN

1. No
2. GP
3. Psychiatrist
4. Physiotherapist
5. Respite
6. Attendant care / personal care
7. In-home accommodation support
8. Alternative family placement services
9. Community support services
10. Behaviour/specialist intervention
11. Therapy
12. Counselling
13. Case management
14. Community access services
15. Learning and life skills development
16. Recreation/holiday programs
17. Disability employment services
18. Carer education or training
19. Advocacy
20. Alternate forms of communication (TTY; print services; Auslan)
21. Referral services
22. Self-help groups
23. Equipment or mobility aides
24. Other (specify)
25. (Don’t know)
26. (Refused)

PRED2 IF D1=CODE 5 (RESPITE) CONTINUE. OTHERS GO TO Eintro

*(IF USED RESPITE)

**D2** For how many hours do you use respite care? IF NECESSARY: You can tell me per week, fortnight, month or year

1. Hours given (specify)
2. (Don’t know) (GO TO D3)
3. (Refused) (GO TO D3)

*(IF ABLE TO SAY NUMBER OF HOURS USED RESPITE FOR)

**D2a** What period does that cover?

1. Week
2. Fortnight
3. Month
4. Year
5. (Don’t know)
6. (Refused)
*PROGRAMMER NOTE: Please insert a check for data entered in D2 and D2a, for example "you have entered 40 hours per month, is that correct?"

1. Yes
2. No GO BACK TO D2 AND D2a TO FIX UP ERROR
E. Support networks – support for the caregiver and person with the disability

E. Intro: I am now going to ask you some questions about the support that YOU RECEIVE from others in your care-giving role. These may include people in your household, family, friends, and the professionals, services and institutions we just asked about…

1. Continue

*PROGRAMMER NOTE: ASK E1, E4, E5, E2 FOR EACH PERSON (UP TO THREE) CARED FOR AT A3.

*PROGRAMMER NOTE: DO NOT DISPLAY OTHER PERSONS IN HOUSEHOLD IN E1 AND SIMILAR FRAMES IF PERSON IS AGED 7 OR UNDER

*(ALL) AIFS - SUP1

E.1 When you need advice about caring for <insert name from A3_1>, who do you turn to? Is there anyone else? (MULTIPLES ACCEPTED)

1. No / None / No one
2. <name from a3_1> IF A5_1>7 (PWD ONE) (SUPPRESS IF A3_1 APPEARS IN QUESTION STEM)
3. <name from a3_2> IF A5_2>7 (PWD TWO) (SUPPRESS IF A3_2 APPEARS IN QUESTION STEM)
4. <name from a3_3> IF A5_3>7 (PWD THREE) (SUPPRESS IF A3_3 APPEARS IN QUESTION STEM)
5. <name from C5_1=1> IF C6>7 (OTHER PERSON IN HOUSEHOLD NUMBER ONE)
6. <name from C5_2=1> IF C6>7 (OTHER PERSON IN HOUSEHOLD NUMBER TWO)
7. <name from C5_3=1> IF C6>7 (OTHER PERSON IN HOUSEHOLD NUMBER THREE)
8. <name from C5_4=1> IF C6>7 (OTHER PERSON IN HOUSEHOLD NUMBER FOUR)
9. <name from C5_5=1> IF C6>7 (OTHER PERSON IN HOUSEHOLD NUMBER FIVE)
10. <name from C5_6=1> IF C6>7 (OTHER PERSON IN HOUSEHOLD NUMBER SIX)
11. <name from C5_7=1> IF C6>7 (OTHER PERSON IN HOUSEHOLD NUMBER SEVEN)
12. <name from C5_8=1> IF C6>7 (OTHER PERSON IN HOUSEHOLD NUMBER EIGHT)
13. Other individual outside household (Specify Name____)
14. Other individual outside household (Specify Name____)
15. Other individual outside household (Specify Name____)
16. Other individual outside household (Specify Name____)
17. Other individual outside household (Specify Name____)
18. Other individual outside household (Specify Name____)
19. Other individual outside household (Specify Name____)
20. Other informal social group (e.g. work colleagues, craft circles, etc.) (Specify____)
21. Other informal social group (e.g. work colleagues, craft circles, etc.) (Specify____)
22. Other professional (Specify____)
23. Other professional (Specify____)
24. Other professional (Specify____)
25. Other service (specify)
26. Other service (specify)
27. Other service (specify)
28. (Not applicable)
29. (Don’t know)
30. (Refused)
E2 When you want to talk about worries and fears about caring for <insert name from A3_1>, who do you turn to? Is there anyone else?
(MULTIPLES ACCEPTED)

*USE FRAME FROM E1 (FILL 13-27 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, ELSE RETAIN AS SPECIFIED OTHER)

*(CLOSE LOOP)*

E6 When you want to talk about any other worries and fears (not related to caring), who do you turn to? Is there anyone else?
(MULTIPLES ACCEPTED)

*USE FRAME FROM E1 (FILL 13-27 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, ELSE RETAIN AS SPECIFIED OTHER)

E3 Who could you ask for help with everyday duties other than caring for
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>
…..by everyday duties we mean things like going to the shops for you, or helping you do some work around the house? Is there anyone else?
(MULTIPLES ACCEPTED)

*USE FRAME FROM E1 (FILL 13-27 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, ELSE RETAIN AS SPECIFIED OTHER)

E7 Aside from any government financial assistance, do you get any extra money to assist with your caring role? IF YES CLARIFY: Which individuals or services do you get the extra money from? Is there anyone else?
(MULTIPLES ACCEPTED)

*USE FRAME FROM E1 (FILL 13-27 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, ELSE RETAIN AS SPECIFIED OTHER)
Now thinking about the support you receive in providing care for <insert name from A3_1>, <insert name from A3_2>, <insert name from A3_3>, ..... overall, do you feel that YOU need... (READ OUT)

1. A lot more support
2. A little more support, or
3. Is the support you are getting now about right?
4. (Don’t know)
5. (Can’t say)

*PROGRAMMER NOTE: ASK E9 AND E10 FOR EACH PERSON (UP TO THREE) CARED FOR AT A3.

I am now going to ask you some questions regarding the support <insert name from A3_1> receives from other people besides you

Who does <insert name from A3_1> turn to when (he/she) wants to talk about worries and fears? Is there anyone else?
(MULTIPLES ACCEPTED)

*USE FRAME FROM E1 (FILL 13-27 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, ELSE RETAIN AS SPECIFIED OTHER)

When <insert name from A3_1> needs advice, who does (he/she) turn to? Is there anyone else?
(MULTIPLES ACCEPTED)

*USE FRAME FROM E1 (FILL 13-27 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, ELSE RETAIN AS SPECIFIED OTHER)

Aside from you, when <insert name from A3_1> needs assistance with self-care, mobility, or communication, who does (he/she) turn to? Is there anyone else?
(MULTIPLES ACCEPTED)

*USE FRAME FROM E1 (FILL 13-27 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, ELSE RETAIN AS SPECIFIED OTHER)

Aside from you, when <insert name from A3_1> needs assistance with household management tasks, who does (he/she) turn to? Is there anyone else?
(MULTIPLES ACCEPTED)

*USE FRAME FROM E1 (FILL 13-27 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, ELSE RETAIN AS SPECIFIED OTHER)

Aside from you, when <insert name from A3_1> needs assistance with household management tasks, who does (he/she) turn to? Is there anyone else?

IF NECESSARY: By household management tasks, we mean things like preparing meals, doing housework, shopping and managing money

*USE FRAME FROM E1 (FILL 13-27 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, ELSE RETAIN AS SPECIFIED OTHER)

*(CLOSE LOOP)
PREE12 IF SUPPORT PROVIDED TO RESPONDENT IN CARING FOR PERSON WITH A
DISABILITY, OR BY ANYONE ELSE IN CARING FOR PERSON WITH A DISABILITY (E1, E4, E5,
E2, E6, E3, E9, E10) CONTINUE. IF NO SUPPORT PROVIDED AT ALL, GO TO PREE13.

*(ALL)
E12 I’d just like to run through all the people you have said provide support to you or
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>,
and get some idea of how many hours they would spend doing this in a typical week.

So in a typical week, about how many hours would <insert statement> spend supporting you
or
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?

*(STATEMENTS)
(CREATE / DISPLAY STATEMENT FOR EACH OTHER HOUSEHOLD MEMBER / SERVICE /
OTHER INDIVIDUAL OUTSIDE HOUSEHOLD / OTHER INFORMAL SOCIAL
GROUP (CODES 2-21) MENTIONED IN SECTION E1 TO E11)
USE CODES FROM E1 (EXCLUDING NO-ONE / PROFESSIONALS (CODES 22-24) /
SERVICES (CODES 25-27) / NOT APPLICABLE / DON’T KNOW / REFUSED)

(RESPONSE FRAME)
1. Hours given (Specify________) (RANGE 0.0 TO 168.0)
2. (Can’t say)
3. (Refused)

PREE13 IF MORE THAN ONE INDIVIDUAL (E1, E4, E5, E2, E6, E3, E9, E10 FRAMES CODES 2
TO 19) PROVIDES SUPPORT TO RESPONDENT OR PERSON WITH A DISABILITY, CONTINUE,
ELSE GO TO E11

*(MORE THAN ONE PERSON PROVIDES SUPPORT TO RESPONDENT OR PWD) (AIFS - SUP10)
E13 The next question focuses on people who provide support to you or
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>

.. So this includes…
DISPLAY NAMES OF ALL PEOPLE FROM E1 TO E11 (CODES 2-19)

E13a On the whole, would you say they co-operate with each other to provide assistance to you or
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?

1. Yes
2. No (GO TO PREE14c)
3. (Can’t say) GO TO E11
4. (Refused) GO TO E11

*(LOOP E14-14b UNTIL CODES 2-4 ARE ANSWERED AT E14, ALLOW UP TO 6 LOOPS. IN
SECOND/ SUBSEQUENT LOOPS DISPLAY “Would there be any OTHER exceptions?”)

*(SUPPORT INDIVIDUALS COMMUNICATE WELL WITH EACH OTHER) (AIFS – SUP11)
E14 Would there be any exceptions? – that is, individuals who do NOT co-operate with each
other?

1. Yes (some don’t co-operate with each other)
2. No (all co-operate with each other) GO TO E11
3. (Can’t say) GO TO E11
4. (Refused ) GO TO E11
E14a CAPTURE DETAILS OF FIRST PERSON WHO DOES NOT CO-OPERATE WELL

*USE FRAME FROM E1 (CODES 2-19, FILL 13-19 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, RETAIN AS SPECIFIED OTHER)

E14b CAPTURE DETAILS OF SECOND PERSON WHO DOES NOT CO-OPERATE WELL

*USE FRAME FROM E1 (CODES 2-19, FILL 13-19 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, RETAIN AS SPECIFIED OTHER) EXCLUDE PERSON MENTIONED IN E14a

*(CLOSE LOOP)

PREE14c IF E13=CODE 2 (INDIVIDUALS DO NOT CO-OPERATE WITH EACH OTHER) CONTINUE. OTHERS GO TO PREE15

*(LOOP E14c-14e UNTIL CODES 2-4 ARE ANSWERED AT E14c, ALLOW UP TO 6 LOOPS. IN SECOND/ SUBSEQUENT LOOPS DISPLAY “Would there be any OTHER exceptions?”)

*(SUPPORT INDIVIDUALS DO NOT CO-OPERATE WELL WITH EACH OTHER) (AIFS – SUP11)

E14c Would there be any exceptions? – that is, individuals who do co-operate with each other?

1. Yes (some co-operate with each other)
2. No (none co-operate with each other) GO TO E11
3. (Can’t say) GO TO E11
4. (Refused) GO TO E11

E14d CAPTURE DETAILS OF FIRST PERSON WHO DOES CO-OPERATE WELL

*USE FRAME FROM E1 (CODES 2-19, FILL 13-19 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, RETAIN AS SPECIFIED OTHER)

E14e CAPTURE DETAILS OF SECOND PERSON WHO DOES CO-OPERATE WELL

*USE FRAME FROM E1 (CODES 2-19, FILL 13-19 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, RETAIN AS SPECIFIED OTHER) EXCLUDE PERSON MENTIONED IN E14d

*(CLOSE LOOP)

*(LOOP (E11) FOR EACH PERSON MENTIONED AT A3)

*(ALL) (AIFS – SUP12)

E11 Are there any family members, friends or other support people who you have had disagreements with about caring for <insert name from A3_1>? (MULTIPLES ACCEPTED)

*USE FRAME FROM E1 (FILL 13-25 WITH TEXT FROM SPECIFIED OTHER, IF NOT USED, ELSE RETAIN AS SPECIFIED OTHER)

*(CLOSE LOOP)
PREE15. IF INDIVIDUALS PROVIDING SUPPORT TO RESPONDENT OR PERSONS WITH A DISABILITY ARE FROM OUTSIDE HOUSEHOLD (ANY CODES 13 TO 19 AT E1 TO E11) CONTINUE. OTHERS GO TO Fintro.

*ASK E15 TO E17 FOR EACH PERSON (13 TO 19) FROM OUTSIDE HOUSEHOLD

*(PERSON FROM OUTSIDE HOUSEHOLD PROVIDES SUPPORT TO RESPONDENT OR PWD)

E15 Just to complete the picture of who provides support to you and

- <insert name from A3_1>
- <insert name from A3_2>
- <insert name from A3_3>

…what is <insert name of first support person (person 13’s)> relationship to you?

1. Son / daughter
2. Step-son / daughter
3. Partner’s son / daughter
4. Parent (including step parent)
5. Parent-in-law
6. Grandparent
7. Grand child
8. Brother / sister
9. Uncle / aunt
10. Friend
11. Friend of person with disability
12. Flatmate/Boarder
13. Nanny/babysitter
14. Neighbour
15. Other provider of support services (GO TO NEXT SUPPORT PERSON ELSE Fintro)
16. Other family (specify)
17. Other (specify_______)
18. (Don’t know)
19. (Refused)

*(INDIVIDUAL OUTSIDE HOUSEHOLD PROVIDES SUPPORT TO RESPONDENT / PERSON WITH DISABILITY)

E16 About how old is <person 13>?

1. Age given (specify) (RANGE 0 TO 110)
2. (Don’t know)
3. (Refused)

*(INDIVIDUAL OUTSIDE HOUSEHOLD PROVIDES SUPPORT TO RESPONDENT / PERSON WITH DISABILITY)

E17 COLLECT GENDER OF <person 13>

1. Male
2. Female
3. (Refused)

*(CLOSE LOOP)
PREE18a IF PERSON 13 PROVIDES ASSISTANCE TO A3_1 (FROM RESPONSES AT E9_1, E10_1, E4_1 OR E5_1), CONTINUE, ELSE GO TO PREE18b

* (INDIVIDUAL OUTSIDE HOUSEHOLD PROVIDES SUPPORT TO RESPONDENT / PERSON WITH DISABILITY)
E18a What is <person 13's> relationship to <insert name from A3_1>?

1. Son / daughter
2. Step-son / daughter
3. Partner's son / daughter
4. Parent (including step parent)
5. Parent-in-law
6. Grandparent
7. Grand child
8. Brother / sister
9. Uncle / aunt
10. Friend
11. Flatmate/Boarder
12. Nanny/babysitter
13. Other family (specify)
14. Other (specify)
15. (Don't know)
16. (Refused)

PREE18b IF PERSON 13 PROVIDES ASSISTANCE TO A3_2 (FROM RESPONSES AT E9_2, E10_2, E4_2 OR E5_2), CONTINUE, ELSE GO TO PREE18c

* (INDIVIDUAL OUTSIDE HOUSEHOLD PROVIDES SUPPORT TO RESPONDENT / PERSON WITH DISABILITY)
E18b What is <person 13's> relationship to <insert name from A3_2>?

1. Do not know each other
2. Son / daughter
3. Step-son / daughter
4. Partner's son / daughter
5. Parent (including step parent)
6. Parent-in-law
7. Grandparent
8. Grand child
9. Brother / sister
10. Uncle / aunt
11. Friend
12. Flatmate/Boarder
13. Nanny/babysitter
14. Other family (specify)
15. Other (specify)
16. (Don't know)
17. (Refused)
PREE18c IF PERSON 13 PROVIDES ASSISTANCE TO A3_3 (FROM RESPONSES AT E9_3, E10_3, E4_3 OR E5_3), CONTINUE, ELSE GO TO PREE19

*(INDIVIDUAL OUTSIDE HOUSEHOLD PROVIDES SUPPORT TO RESPONDENT / PERSON WITH DISABILITY)*

E18c What is <person 13's> relationship to <insert name from A3_3>?

1. Do not know each other
2. Son / daughter
3. Step-son / daughter
4. Partner's son / daughter
5. Parent (including step parent)
6. Parent-in-law
7. Grandparent
8. Grand child
9. Brother / sister
10. Uncle / aunt
11. Friend
12. Flatmate/Boarder
13. Nanny/babysitter
14. Other family (specify)
15. Other (specify)
16. (Don't know)
17. (Refused)
**F. Family life events**

PREFIntro IF NOT LIVING ALONE (C4 = CODES 1-8 OR A8 = CODES 1-2) INSERT < or current members of your household> INTO QUESTION STEM

Fintro The next set of questions asks you about events that you (or current members of your household) may have experienced. Again, we are interested in understanding how caring duties may impact on family relationships…. So, SINCE YOU FIRST STARTED caring for <insert name from A3_1> <insert name from A3_2> <insert name from A3_3> ….have you…

1. Continue

PREF1a IF DUM1 = 2 (NO CURRENT PARTNER) CONTINUE. OTHERS GO TO PREF1b

*(NO CURRENT PARTNER)

F1a1 Had a spouse or long term partner?

1. Yes
2. No GO TO PREF1c (IE NO RESPONDENT SEPARATIONS / RECONCILIATIONS TO ASK ABOUT, ASK ABOUT OTHER SEPARATIONS IN HHLD)
3. (Refused) GO TO PREF1c (IE NO RESPONDENT SEPARATIONS / RECONCILIATIONS TO ASK ABOUT, ASK ABOUT OTHER SEPARATIONS IN HHLD)

*(HAS HAD PARTNER SINCE CARING)

F1a2 And have you separated from a spouse or long-term partner since you first started caring for <insert name from A3_1> <insert name from A3_2> <insert name from A3_3>?

1. Yes GO TO PREF1w
2. No GO TO PREF2
3. (Refused) GO TO PREF2

PREF1b IF DUM1 = 1 (CURRENTLY HAS PARTNER) GO TO F1b
OTHERS GO TO PREF1c

*(CURRENTLY HAS PARTNER)

F1b Separated from a spouse or long-term partner, or have you had the same partner the whole time, with no separations?

1. Separated
2. Had the same partner the whole time GO TO PREF1c (IE NO RESPONDENT SEPARATIONS / RECONCILIATIONS TO ASK ABOUT, ASK ABOUT OTHER SEPARATIONS IN HHLD)
3. (Refused) GO TO PREF1c (IE NO RESPONDENT SEPARATIONS / RECONCILIATIONS TO ASK ABOUT, ASK ABOUT OTHER SEPARATIONS IN HHLD)

PREF1w IF F1a2 = 1 OR F1b = 1 (SEPARATED) CONTINUE. OTHERS GO TO PREF1c

*(SEPARATED)

F1w Who did you separate from?

1. Insert name of partner (name provided at (A3 IF A4 = CODE 1 OR 2) OR (C5 IF C8 = CODES 1 OR 2)
2. Other (specify)
3. (Refused)
In what year was that?

1. Year given (specify) (RANGE: 2006 TO YEAR FIRST STARTED CARING FOR PWD AT A9y, IF THERE ARE MULTIPLE PWDs USE EARLIEST YEAR)
2. (Don’t know year)
3. (Refused)

PREF2 IF F1a2=2 OR 3 (NOT SEPARATED) INSERT < Please bear with me, we ask everyone this question, even if they haven’t separated> INTO QUESTION STEM

*(F1a1=code 1 or F1b=code 1)
F2 (Please bear with me, we ask everyone this question, even if they haven’t separated) And Since you first started caring for
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>
....have you got back together with a spouse or long term partner?

1. Yes
2. No GO TO PREF1c
3. (Refused) GO TO PREF1c

*(RECONCILIATION)
F2w Who did you get back together with?

1. Insert name of partner (name provided at (A3 IF A4=CODE 1 OR 2) OR (C5 IF C8 CODES 1 OR 2)
2. Other (specify)
3. (Refused)

*(RECONCILIATION)
F2y In what year was that?

1. Year given (specify) (RANGE: 2006 TO YEAR FIRST STARTED CARING FOR PWD AT A9y)
2. (Don’t know year)
3. (Refused)

PREF1c IF (C4 =CODES 1-8 AND C5>17) OR (A8=CODES 1-2 AND A5>17) (OTHER HOUSEHOLD MEMBERS AGED 18 OR OVER) CONTINUE. OTHERS GO TO PREF2a

PREF1c IF F1b=CODE 2 AND C8=CODES 1 OR 2 OR A4=CODES 1 OR 2 AND ONLY OTHER HOUSEHOLD MEMBER IS PARTNER / HUSBAND / WIFE GO TO PREF2a. (IE IF ONLY OTHER ADULT IN HOUSEHOLD IS CARER’S PARTNER AND THEY HAVE BEEN TOGETHER THE WHOLE TIME SKIP THIS QUESTION)

*LOOP (F1c-F1cm) UP TO THREE TIMES

*(OTHER HOUSEHOLD MEMBERS AGED 18 OR OVER)
F1c Has any other adult in your current household separated from a spouse or long term partner since you first started caring for
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>? ?

1. Yes
2. No GO TO PREF2a
3. (Don’t know) GO TO PREF2a
4. (Refused) GO TO PREF2a
*(SEPARATION IN HOUSEHOLD)
F1c1 SPECIFY FIRST PERSON IN SEPARATION 1

1. DISPLAY PWD FROM A3_1 IF A5>17
2. DISPLAY PWD FROM A3_2 IF A5>17
3. DISPLAY PWD FROM A3_3 IF A5>17
4. DISPLAY HOUSEHOLD MEMBER 1 FROM C5 IF C6>17
5. DISPLAY HOUSEHOLD MEMBER 2 FROM C5 IF C6>17
6. DISPLAY HOUSEHOLD MEMBER 3 FROM C5 IF C6>17
7. DISPLAY HOUSEHOLD MEMBER 4 FROM C5 IF C6>17
8. DISPLAY HOUSEHOLD MEMBER 5 FROM C5 IF C6>17
9. DISPLAY HOUSEHOLD MEMBER 6 FROM C5 IF C6>17
10. DISPLAY HOUSEHOLD MEMBER 7 FROM C5 IF C6>17
11. DISPLAY HOUSEHOLD MEMBER 8 FROM C5 IF C6>17
12. Other (Specify name__________
13. (Refused)

*(SEPARATION IN HOUSEHOLD)
F1c2 SPECIFY SECOND PERSON IN SEPARATION 1

DO NOT DISPLAY PERSON FROM F1c1

1. DISPLAY PWD FROM A3_1 IF A5>17
2. DISPLAY PWD FROM A3_2 IF A5>17
3. DISPLAY PWD FROM A3_3 IF A5>17
4. DISPLAY HOUSEHOLD MEMBER 1 FROM C5 IF C6>17
5. DISPLAY HOUSEHOLD MEMBER 2 FROM C5 IF C6>17
6. DISPLAY HOUSEHOLD MEMBER 3 FROM C5 IF C6>17
7. DISPLAY HOUSEHOLD MEMBER 4 FROM C5 IF C6>17
8. DISPLAY HOUSEHOLD MEMBER 5 FROM C5 IF C6>17
9. DISPLAY HOUSEHOLD MEMBER 6 FROM C5 IF C6>17
10. DISPLAY HOUSEHOLD MEMBER 7 FROM C5 IF C6>17
11. DISPLAY HOUSEHOLD MEMBER 8 FROM C5 IF C6>17
12. Other (Specify name__________
13. (Refused)

F1cy In what year was that?

1. Year given (specify) (RANGE: 2006 TO YEAR FIRST STARTED CARING FOR PWD AT A9y, IF THERE ARE MULTIPLE PWDs USE EARLIEST YEAR)
2. (Don't know year)
3. (Refused)

*(CLOSE LOOP)

PREF2a IF (C4 =CODES 1-8 AND C5>17) OR (A8=CODES 1-2 AND A5>17) (OTHER HOUSEHOLD MEMBERS AGED 18 OR OVER) CONTINUE. OTHERS GO TO PREF3

PREF2a IF F1b=CODE 2 AND C8=CODES 1 OR 2 OR A4=CODES 1 OR 2 AND ONLY OTHER HOUSEHOLD MEMBER IS PARTNER / HUSBAND / WIFE GO TO PREF3. (IE IF ONLY OTHER ADULT IN HOUSEHOLD IS CARER'S PARTNER AND THEY HAVE BEEN TOGETHER THE WHOLE TIME SKIP THIS QUESTION)

*LOOP (F2a-F2am) UP TO THREE TIMES OR UNTIL F2a=CODES 2-4

*(OTHER HOUSEHOLD MEMBERS AGED 18 OR OVER)
F2a Has any other adult in your current household gotten back with a spouse or long term partner since you first started caring for

<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?

1. Yes
2. No GO TO PREF3
3. (Don’t know) GO TO PREF3
4. (Refused) GO TO PREF3
*(RECONCILIATION IN HOUSEHOLD)
F2a1  SPECIFY FIRST PERSON IN RECONCILIATION 1

1. DISPLAY PWD FROM A3_1 IF A5>17
2. DISPLAY PWD FROM A3_2 IF A5>17
3. DISPLAY PWD FROM A3_3 IF A5>17
4. DISPLAY HOUSEHOLD MEMBER 1 FROM C5 IF C6>17
5. DISPLAY HOUSEHOLD MEMBER 2 FROM C5 IF C6>17
6. DISPLAY HOUSEHOLD MEMBER 3 FROM C5 IF C6>17
7. DISPLAY HOUSEHOLD MEMBER 4 FROM C5 IF C6>17
8. DISPLAY HOUSEHOLD MEMBER 5 FROM C5 IF C6>17
9. DISPLAY HOUSEHOLD MEMBER 6 FROM C5 IF C6>17
10. DISPLAY HOUSEHOLD MEMBER 7 FROM C5 IF C6>17
11. DISPLAY HOUSEHOLD MEMBER 8 FROM C5 IF C6>17
12. Other (Specify name__________)
13. (Refused)

*(RECONCILIATION IN HOUSEHOLD)
F2a2  SPECIFY SECOND PERSON IN RECONCILIATION 1

DO NOT DISPLAY PERSON FROM F2a

1. DISPLAY PWD FROM A3_1 IF A5>17
2. DISPLAY PWD FROM A3_2 IF A5>17
3. DISPLAY PWD FROM A3_3 IF A5>17
4. DISPLAY HOUSEHOLD MEMBER 1 FROM C5 IF C6>17
5. DISPLAY HOUSEHOLD MEMBER 2 FROM C5 IF C6>17
6. DISPLAY HOUSEHOLD MEMBER 3 FROM C5 IF C6>17
7. DISPLAY HOUSEHOLD MEMBER 4 FROM C5 IF C6>17
8. DISPLAY HOUSEHOLD MEMBER 5 FROM C5 IF C6>17
9. DISPLAY HOUSEHOLD MEMBER 6 FROM C5 IF C6>17
10. DISPLAY HOUSEHOLD MEMBER 7 FROM C5 IF C6>17
11. DISPLAY HOUSEHOLD MEMBER 8 FROM C5 IF C6>17
12. Other (Specify name__________)
13. (Refused)

*(RECONCILIATION IN HOUSEHOLD)
F2ay  In what year was that?

1. Year given (specify) (RANGE: 2006 TO YEAR FIRST STARTED CARING FOR PWD AT A9y)
2. (Don’t know year)
3. (Refused)

*(CLOSE LOOP)
PREF3 IF DUM1=1 OR F1a1=CODE 1 (HAVE OR HAVE HAD A PARTNER SINCE CARING FOR PWD) CONTINUE. OTHERS GO TO F4

*(HAD PARTNER AT ANY TIME SINCE STARTED CARING) (AIFS – LE3)
F3  (Since you started your caring duties, just confirming…) Was there a period or periods in your life when the number of arguments with your spouse or partner increased significantly?

1. Yes
2. No (GO TO F4)
3. (Refused) (GO TO F4)
4. (Not applicable / never been partnered whilst caring) (GO TO F4)
*(HAD ARGUMENTS)

F3y1 When was that?

1. DISPLAY YEAR WHEN RESPONDENT WAS 15 YEARS (C1+15) (GO TO F3y2)
2. Other year given (Specify____) (RANGE (C1+15 TO 2006) (GO TO F3y2)
3. Year range given (GO TO F3y1a)
4. Multiple individual years given (GO TO F3y1b)
5. (Don’t know year) (GO TO F3y2)
6. (Refused) (GO TO F4)

*(GAVE A RANGE OF YEARS IN F3y1)
F3y1a CAPTURE FIRST YEAR GIVEN

1. First year given (specify) (RANGE C1+15 TO 2006)

CAPTURE SECOND YEAR GIVEN

1. Second year given (specify) (RANGE YEAR GIVEN AS FIRST YEAR+1 TO 2006)

PREF3y1b IF F3y1=CODE 4 (MULTIPLE YEARS GIVEN) CONTINUE. OTHERS GO TO PREF3y2.

*(GAVE MULTIPLE YEARS IN F3y1)
F3y1b CAPTURE YEARS GIVEN (ACCEPT MULTIPLES)

*PROGRAMMER NOTE: DISPLAY CODE FRAME AS 4 COLUMNS

1. List of years (RANGE C1+15 TO 2006)

PRE F3y2 IF F3=CODE 1 AND F3y1=CODES 1, 2, 3 OR 5 (HAD ARGUMENTS IN SPECIFIC TIME FRAME) CONTINUE. OTHERS GO TO F4

*(HAD ARGUMENTS IN SPECIFIC TIME FRAME)
F3y2 Were there any other times after starting your caring duties when the number of arguments with your spouse or partner increased significantly

1. DISPLAY YEAR WHEN RESPONDENT WAS 15 YEARS (C1+15) GO TO F4
2. Year given (Specify____) GO TO F4
3. Year range given
4. No others GO TO F4
5. (Don’t know year) GO TO F4
6. (Refused) GO TO F4

*(GAVE A RANGE OF YEARS IN F3y2)
F3y2a CAPTURE FIRST YEAR GIVEN

1. First year given (specify) (RANGE C1+15 TO 2006)

CAPTURE SECOND YEAR GIVEN

1. Second year given (specify) (RANGE YEAR GIVEN AS FIRST YEAR+1 TO 2006)

*(ALL) (AIFS – LE4)
F4 Since you first started your caring duties, have you experienced a period of 6 months or more when YOU felt depressed or sad most days, even if you felt okay sometimes?

1. Yes
2. No (GO TO PREF5)
3. (Refused) (GO TO PREF5)
*(HAD TIMES WHEN FELT DEPRESSED OR SAD MOST DAYS)

F4y1  In which year was that?

1. DISPLAY YEAR WHEN RESPONDENT WAS 4 YEARS (C1+4) (GO TO F4y2)
2. Other year given (Specify____) (RANGE C1+4 TO 2006) (GO TO F4y2)
3. Year range given (GO TO F4y1a)
4. Multiple individual years given (GO TO F4y1b)
5. (Don’t know year) (GO TO F4y2)
6. (Refused) (GO TO F5)

*(GAVE A RANGE OF YEARS IN F4y1)

F4y1a  CAPTURE FIRST YEAR GIVEN

1. First year given (specify) (RANGE C1+4 TO 2006)

CAPTURE SECOND YEAR GIVEN

1. Second year given (specify) (RANGE YEAR GIVEN AS FIRST YEAR+1 TO 2006)

PREF4y1b IF F4y1=CODE 4 (MULTIPLE YEARS GIVEN) CONTINUE. OTHERS GO TO PREF4y2.

*(GAVE MULTIPLE YEARS IN F4y1)

F4y1b  CAPTURE YEARS GIVEN (ACCEPT MULTIPLES)

*PROGRAMMER NOTE: DISPLAY CODE FRAME AS 4 COLUMNS

1. List of years (RANGE C1+4 TO 2006)

PRE F4y2 IF F4=CODE 1 AND F4y1=CODES 1, 2, 3 OR 5 (HAD TIMES WHEN FELT SAD OR DEPRESSED MOST DAYS IN SPECIFIC TIME FRAME) CONTINUE. OTHERS GO TO PREF5

*(HAD TIMES WHEN FELT DEPRESSED OR SAD MOST DAYS IN SPECIFIC TIME FRAME)

F4y2  Were there any other times after starting your caring duties when you experienced a period of 6 months or more when YOU felt depressed or sad most days, even if you felt okay sometimes

1. DISPLAY YEAR WHEN RESPONDENT WAS 4 YEARS (C1+4) GO TO PREF5
2. Year given (Specify____) GO TO PREF5
3. Year range given
4. No others GO TO PREF5
5. (Don’t know year) GO TO PREF5
6. (Refused) GO TO PREF5

*(GAVE A RANGE OF YEARS IN F4y2)

F4y2a  CAPTURE FIRST YEAR GIVEN

1. First year given (specify) (RANGE C1+4 TO 2006)

CAPTURE SECOND YEAR GIVEN

1. Second year given (specify) (RANGE YEAR GIVEN AS FIRST YEAR+1 TO 2006)
PREF5 IF AT LEAST ONE OTHER PERSON LIVING IN HOUSEHOLD AGED 4 OR OVER INCLUDING PWD ((C4=CODES 1-8 AND C5>3) OR (A8=1 OR 2 AND A5>3)) CONTINUE. OTHERS GO TO G1

*(AT LEAST ONE OTHER PERSON LIVING IN HOUSEHOLD AGED 4 OR OVER INCLUDING PWD) (AIFS – LE5)

F5 And since you started your caring duties, is there a HOUSEHOLD MEMBER who has experienced a period of 6 months or more when they felt depressed or sad most days, even when they felt okay sometimes?

INTERVIEWER NOTE: Can include the person with a disability if they live in the same household as respondent

1. Yes
2. No (GO TO G1)
3. (Refused) (GO TO G1)

F5a Who was that?
(SINGLE RESPONSE)

DISPLAY NAMES OF OTHER PERSONS IN HOUSEHOLD AND NAME OF PWD IF LIVES IN SAME HOUSEHOLD AS RESPONDENT. INCLUDE OTHER SPECIFY OPTION

*(HAD TIMES WHEN OTHER HOUSEHOLD MEMBER FELT DEPRESSED OR SAD MOST DAYS)
F5y1 In which year was that?

1. DISPLAY YEAR WHEN HOUSEHOLD MEMBER WAS 4 YEARS (C6+4 OR A5+4) (GO TO F5b)
2. Other year given (Specify____) (RANGE C6+4 OR A5+4 TO 2006) (GO TO F5b)
3. Year range given (GO TO F5y1a)
4. Multiple individual years given (GO TO F5y1b)
5. (Don’t know year) (GO TO F5b)
6. (Refused) (GO TO F5b)

*(GAVE A RANGE OF YEARS IN F5y1)
F5y1a CAPTURE FIRST YEAR GIVEN

1. First year given (specify) (RANGE C6+4 OR A5+4 TO 2006)

CAPTURE SECOND YEAR GIVEN

1. Second year given (specify) (RANGE YEAR GIVEN AS FIRST YEAR+1 TO 2006)

PREF5y1b IF F5y1=CODE 4 (MULTIPLE YEARS GIVEN) CONTINUE. OTHERS GO TO PREF5b.

*(GAVE MULTIPLE YEARS IN F5y1)
F5y1b CAPTURE YEARS GIVEN (ACCEPT MULTIPLES)

*PROGRAMMER NOTE: DISPLAY CODE FRAME AS 4 COLUMNS

1. List of years (RANGE C6+4 OR A5+4 TO 2006)
PRE F5b IF F5=CODE 1 (HAD TIMES WHEN HOUSEHOLD MEMBER FELT SAD OR DEPRESSED MOST DAYS) CONTINUE. OTHERS GO TO G1

*(HAD TIMES WHEN OTHER HOUSEHOLD MEMBER FELT DEPRESSED OR SAD MOST DAYS)

F5b Were there any other times after starting your caring duties when another household member a period of 6 months or more when they felt depressed or sad most days, even if they felt okay sometimes

1. Yes
2. No (GO TO G1)
3. (Refused) (GO TO G1)

F5c Who was that?
(SINGLE RESPONSE)

DISPLAY NAMES OF OTHER PERSONS IN HOUSEHOLD AND NAME OF PWD IF LIVES IN SAME HOUSEHOLD AS RESPONDENT. INCLUDE OTHER SPECIFY OPTION

*(HAD TIMES WHEN OTHER HOUSEHOLD MEMBER FELT DEPRESSED OR SAD MOST DAYS)

F5y2 In which year was that?

1. DISPLAY YEAR WHEN HOUSEHOLD MEMBER WAS 4 YEARS (C6+4 OR A5+4) GO TO PREF5d
2. Other year given (Specify____) (RANGE C6+4 OR A5+4 TO 2006) GO TO PREF5d
3. Year range given (GO TO F5y2a)
4. Multiple individual years given (GO TO F5y2b)
5. (Don’t know year) (GO TO PREF5d)
6. (Refused) (GO TO PREF5d)

*(GAVE A RANGE OF YEARS IN F5y2)

F5y2a CAPTURE FIRST YEAR GIVEN

1. First year given (specify) (RANGE C6+4 OR A5+4 TO 2006)

CAPTURE SECOND YEAR GIVEN

1. Second year given (specify) (RANGE YEAR GIVEN AS FIRST YEAR+1 TO 2006)

PREF5y2b IF F5y2=CODE 4 (MULTIPLE YEARS GIVEN) CONTINUE. OTHERS GO TO PREF5d.

*(GAVE MULTIPLE YEARS IN F5y1)

F5y1b CAPTURE YEARS GIVEN (ACCEPT MULTIPLES)

*PROGRAMMER NOTE: DISPLAY CODE FRAME AS 4 COLUMNS

1. List of years (RANGE C6+4 OR A5+4 TO 2006)

PREF5d IF F5b=CODE 1 AND C4=CODES 3-8 (HAD TIMES WHEN OTHER HOUSEHOLD MEMBER FELT SAD OR DEPRESSED MOST DAYS AND HAD 3 OTHERS LIVING IN HOUSEHOLD) CONTINUE. OTHERS GO TO G1

*(HAD TIMES WHEN OTHER HOUSEHOLD MEMBER FELT DEPRESSED OR SAD MOST DAYS)

F5d Were there any other times after starting your caring duties when another household member a period of 6 months or more when they felt depressed or sad most days, even if they felt okay sometimes?

1. Yes
2. No (GO TO G1)
3. (Refused) (GO TO G1)

F5e Who was that?
(SINGLE RESPONSE)
DISPLAY NAMES OF OTHER PERSONS IN HOUSEHOLD AND NAME OF PWD IF LIVES IN SAME HOUSEHOLD AS RESPONDENT. INCLUDE OTHER SPECIFY OPTION

*(HAD TIMES WHEN OTHER HOUSEHOLD MEMBER FELT DEPRESSED OR SAD MOST DAYS)

F5ey2 In which year was that?

1. DISPLAY YEAR WHEN HOUSEHOLD MEMBER WAS 4 YEARS (C6+4 OR A5+4)
   GO TO G1
2. Other year given (Specify____) (RANGE C6+4 OR A5+4 TO 2006) GO TO G1
3. Year range given (GO TO F5ey2a)
4. Multiple individual years given (GO TO F5ey2b)
5. (Don’t know year) (GO TO G1)
6. (Refused) (GO TO G1)

*(GAVE A RANGE OF YEARS IN F5ey2)

F5ey2a CAPTURE FIRST YEAR GIVEN

1. First year given (specify) (RANGE C6+4 OR A5+4 TO 2006)

CAPTURE SECOND YEAR GIVEN

1. Second year given (specify) (RANGE YEAR GIVEN AS FIRST YEAR+1 TO 2006)

PREF5ey2b IF F5ey2=CODE 4 (MULITIPLE YEARS GIVEN) CONTINUE. OTHERS GO TO G1.

*(GAVE MULTIPLE YEARS IN F5ey1)

F5ey1b CAPTURE YEARS GIVEN (ACCEPT MULTIPLES)

*PROGRAMMER NOTE: DISPLAY CODE FRAME AS 4 COLUMNS

1. List of years (RANGE C6+4 OR A5+4 TO 2006)
G. Family relationships

*(ALL) (AIFS F1-F6)

G1 Now some questions about family life. Please indicate how satisfied or dissatisfied you are with each of the following relationships on a scale from 0 to 10, where 0 is completely dissatisfied and 10 is completely satisfied. We read the same relationships to everyone, so please tell me if they don’t apply to you….

*DISPLAY SCALE FOR EACH STATEMENT '0 is completely dissatisfied and 10 is completely satisfied”

How satisfied are you with:

(STATEMENTS)
a) Your relationship with your partner? (ONLY DISPLAY IF C8=1 OR 2 HUSBAND / WIFE / PARTNER WHO IS NOT THE PERSON WITH A DISABILITY)
b) Your relationship with <insert name from A3_1)?
c) Your relationship with <insert name from A3_2)? (DO NOT DISPLAY IF NO PERSON A3_2)
d) Your relationship with <insert name from A3_3)? (DO NOT DISPLAY IF NO PERSON A3_3)
e) Your relationship with your children (not including <insert name from A3 IF A4=CODES 3-5>?) (IF NECESSARY: this includes step children and partner’s children and children not living with you)
f) Your partner’s relationship with your children? (ONLY DISPLAY IF C8=1, 2 AND G1e NOT 11) (IE RESPONDENT HAS PARTNER IN HOUSEHOLD AND RESPONDENT HAS CHILDREN)
g) How well the children in the household get along with each other? (ONLY DISPLAY IF DUM2=2 AND C6<18) OR (DUM2=1 OR 2 AND C6<18 AND A4=3-5 AND A5<18) (MORE THAN ONE CHILD IN HOUSEHOLD AGED 18 OR UNDER INCLUDING PWD)
h) Your relationship with your parents? (SUPPRESS IF PWD IS PARENT (A4=CODE 6)

(RESPONSE FRAME)

0. 0
1. 1
2. 2
3. 3
4. 4
5. 5
6. 6
7. 7
8. 8
9. 9
10. 10
11. (Not applicable)
12. (Don’t know)
13. (Refused)

*(ALL) (AIFS F7-F10)

G2 To what extent do you agree or disagree that the following statements currently describe your family? PROBE Is that strongly or just? (INTERVIEWER NOTE: Family is to be self defined by the respondent)

(STATEMENTS)
a) There is a feeling of togetherness in the family
b) There is a lot of tension in our family
c) We talk about our personal problems and help each other deal with them
d) Our family copes with and recovers from times of hardship
e) Our family tries new ways of dealing with problems

(RESPONSE FRAME)

1. Strongly agree
2. Agree
3. Disagree
4. Strongly disagree
5. (Don’t know)
6. (Refused)
*(ALL) (AIFS SF1)
H1 In general, would you say your health is … (READ OUT)

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor
6. (Don’t know)
7. (Refused)

*(ALL) (AIFS SF2)
H2 These questions are about how you feel and how things have been with you DURING THE PAST 4 WEEKS. For each question please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks … (READ OUT)

(STATEMENTS)
  a) Did you feel full of life?
  b) Have you been a very nervous person?
  c) Have you felt so down in the dumps that nothing could cheer you up?
  d) Have you felt calm and peaceful?
  e) Did you have a lot of energy?
  f) Have you felt down?
  g) Did you feel worn out?
  h) Have you been a happy person?
  i) Did you feel tired?

(RESPONSE FRAME)
1. All of the time
2. Most
3. A good bit
4. Some
5. A little or
6. None of the time
7. (Don’t know)
8. (Refused)
I. About your social life

*(ALL) (AIFS SL1)
I1 In general, about how often DO YOU get together socially with friends or relatives NOT living with you? (PROBE TO CLARIFY)

1. Every day
2. Several times a week
3. About once a week
4. 2 or 3 times a month
5. About once a month
6. Once or twice every 3 months
7. Less often than once every 3 months
8. (Don’t know)
9. (Refused)

*(ALL) (AIFS SL2)
I2 Would you like to get together … (READ OUT)

1. More often
2. About the same
3. Less often
4. (Don’t know)
5. (Refused)

*(ALL) (AIFS SL3)
I3 In general, about how often DO YOU talk to or email friends or relatives not living with you? (PROBE TO CLARIFY)

1. Every day
2. Several times a week
3. About once a week
4. 2 or 3 times a month
5. About once a month
6. Once or twice every 3 months
7. Less often than once every 3 months
8. (Don’t know)
9. (Refused)
**J. About education**

*(ALL) (AIFS Ed1)*

J1 Now I have a few questions about your education. Firstly, what was the highest year of primary or secondary school you completed?

1. Year 12 or equivalent
2. Year 11 or equivalent
3. Year 10 or equivalent
4. Year 9 or equivalent
5. Year 8 or below
6. Never attended school
7. Still at school (GO TO J3)
8. (Don’t know)
9. (Refused)

*(ALL WHO ARE NOT CURRENTLY AT PRIMARY OR SECONDARY SCHOOL) (AIFS Ed2)*

J2 What is the highest qualification that you have completed?

1. Trade, apprenticeship or workplace training
2. Certificate level I-IV or don’t know level
3. Diploma (2 years full time or equivalent)
4. Associate degree
5. Advanced diploma (3 years full time or equivalent)
6. Bachelor degree but not honours
7. Honours bachelor degree
8. Graduate certificate
9. Graduate diploma
10. Masters degree
11. Doctorate
12. Other (specify)
13. None / Not applicable / school qualification only
14. (Don’t know)
15. (Refused)

*PROGRAMMER INSTRUCTION: IF MULTIPLE PERSON HOUSEHOLD (C4=CODES 1-8 AND C6>14) INCLUDE <or current members of your household> IN QUESTION STEM*

*(ALL) (AIFS Ed3)*

J3 Has caring for...
<br>
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>
<br>
……meant that you (or current members of your household) have had to give up educational opportunities? (NOTE TO INTERVIEWERS: code missed VOCATIONAL opportunities only)

1. Yes
2. No (GO TO K1)
3. (Don’t know) (GO TO K1)
4. (Refused) (GO TO K1)
*IF HOUSEHOLD IS COMPRISED OF JUST CARER AND PWD (C4=CODE 9) THEN AUTOFILL J3a WITH “Myself” AND GO TO J4

*(PERSON(S) IN HOUSEHOLD HAD TO GIVE UP EDUCATIONAL OPPORTUNITIES)

J3a Could you please tell me who had to give up educational opportunities? (PROMPT: Anyone else?) (ACCEPT MULTIPLES)

1. Myself / respondent
2. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_1 IF C6>14) NUMBER ONE
3. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_2 IF C6>14) NUMBER TWO
4. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_3 IF C6>14) NUMBER THREE
5. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_4 IF C6>14) NUMBER FOUR
6. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_5 IF C6>14) NUMBER FIVE
7. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_6 IF C6>14) NUMBER SIX
8. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_7 IF C6>14) NUMBER SEVEN
9. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_8 IF C6>14) NUMBER EIGHT
10. (Refused)

*ASK FOR EACH MENTIONED AT J3a

*(GAVE UP EDUCATIONAL OPPORTUNITY) (AIFS Ed4)

J4 What educational opportunity did <insert name from J3a> give up? (INTERVIEWER NOTE: if a person has enrolled and then dropped out of course then code as not COMPLETED, if not enrolled then code as not UNDERTAKEN)

1. Not complete secondary school
2. Not UNDERTAKEN training for a trade
3. Not COMPLETED training for a trade
4. Not UNDERTAKEN bachelors degree at university
5. Not COMPLETED bachelors degree at university
6. Not UNDERTAKEN n a postgraduate degree at university
7. Not COMPLETED a postgraduate degree at university
8. Not UNDERTAKEN another educational opportunity
9. Not COMPLETED another educational opportunity
10. (Don’t know)
11. (Refused)

*[CLOSE LOOP FOR THOSE WHO GAVE UP EDUCATIONAL OPPORTUNITIES]*
**K. About work**

*(ALL)*

K1    Now I have a few questions about work, and how caring duties may impact on employment…

Since you started your caring duties, have you been able to do any paid work at all?

1. Yes
2. No (GO TO PREK1b)
3. (Don’t know)
4. (Refused)

*(WORKED AT ALL SINCE STARTING CARER DUTIES) (AIFS CGWK)*

K1a    And last week, did you have a full-time or part-time job of any kind? (PROBE TO CLARIFY)

1. Yes, worked for payment or profit GO TO PREK2
2. Yes, but absent on holidays, on paid leave, on strike or temporarily stood down GO TO PREK2
3. Yes, unpaid work in a family business GO TO PREK2
4. Yes, other unpaid work GO TO PREK2
5. Yes, on call but did not work GO TO PREK2
6. No
7. (Refused) (GO TO PREK9)

PRE K1b IF K1=CODE 2 OR K1a=CODE 6 AND C1<66 (CARERS NOT CURRENTLY WORKING AGED 65 OR LESS) CONTINUE. OTHERS GO TO PREK2

*(CARERS NOT CURRENTLY WORKING)*

K1b    Did you actively look for work at any time in the last four weeks?

1. Was looking for full time work in the last 4 weeks GO TO PREK9
2. Was looking for part time work in the last 4 weeks GO TO PREK9
3. No, did not look for work in the last 4 weeks GO TO PREK9
4. No, I’m retired GO TO PREK9
5. (Don’t know) GO TO PREK9
6. (Refused) GO TO PREK9

PREK2 IF K1a=CODES 1-5 (HAD A JOB LAST WEEK) CONTINUE. OTHERS GO TO PREK9

*(HAD A JOB LAST WEEK) (AIFS S%HRSWK1)*

K2    About how many hours per week do YOU usually work in all jobs, including paid or unpaid overtime? NB: If irregular hours, average over last 4 weeks. Do not include travel time to and from place of work.

1. Hours given (specify) (RANGE 0.0 TO 130.0)
2. (Don’t know)
3. (Refused)

*(HAD A JOB LAST WEEK) (AIFS W1)*

K3    Are you considering leaving your job to care for….

<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?

1. Yes
2. No GO TO K4a
3. (Don’t know) GO TO K4a
4. (Refused) GO TO K4a
*(CARERS CONSIDERING LEAVING JOB) (AIFS W2)

K4 What is the MAIN reason you are considering leaving your job to care for
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?  
1. No appropriate disability care arrangements available  
2. Financial considerations/cost of alternative disability care arrangements  
3. Unable to change working arrangements  
4. Emotional obligations  
5. Prefer to care full-time  
6. Overloaded with work and caring responsibilities  
7. Other (Specify_____)  
8. (Don’t know)  
9. (Refused)

*(HAD A JOB LAST WEEK)

K4a And have you ever had to give up work to care for  
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?  
1. Yes  
2. No  GO TO K5  
3. (Don’t know)  GO TO K5  
4. (Refused)  GO TO K5

*(HAD TO GIVE UP WORK)

K4b What was the MAIN reason you gave up work to care for  
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?  
(INTERVIEWER NOTE: If respondent answers person’s health say "Aside from <PWD>‘s health, what circumstances led you to give up work?")
1. No appropriate disability care arrangements available  
2. Financial considerations/cost of alternative disability care arrangements  
3. Unable to change working arrangements  
4. Emotional obligations  
5. Prefer to care full-time  
6. Overloaded with work and caring responsibilities  
7. Other (Specify_____)  
8. (Don’t know)  
9. (Refused)

*(HAD A JOB LAST WEEK) (AIFS W9)

K5 Has caring for..  
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>  
...meant that you have had to change jobs or working arrangements? IF NECESSARY: By this we mean reducing hours, adopting flexible hours or quitting a job or taking up another position that provides shorter or more flexible hours.  
1. Yes  
2. No  
3. (Refused)
*(HAD A JOB LAST WEEK) (AIFS W10)
K6 Has caring for
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>
.....meant that you have had to take periods of leave?

1. Yes
2. No  GO TO PREK15
3. (Refused)  GO TO PREK15

PREK9 IF K1=CODE 2 OR K1a=CODES 6 OR 7 (CARERS NOT CURRENTLY WORKING) CONTINUE. OTHERS GO TO PREK15

*(CARERS NOT CURRENTLY WORKING) (AIFS W3)
K9 Were you employed just before you began to care for
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?

1. Yes
2. No  GO TO K13
3. (Don’t know)  GO TO K13
4. (Refused) GO TO K13

*(LEFT JOB JUST BEFORE BEGAN CARING) (AIFS W4)
K10 Was providing care for
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>
....the MAIN reason you left your job?

1. Yes
2. No  GO TO K13
3. (Don’t know)  GO TO K13
4. (Refused) GO TO K13

*(LEFT JOB TO CARE) (AIFS W5)
K11 What was the MAIN reason you needed to leave your job to care for
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>

(INTerviewER NOTE: If respondent answers person’s health say "Aside from <PWD>‘s health, what circumstances led you to give up work?")

1. No alternative disability care arrangements available
2. Financial considerations/cost of alternative disability care arrangements
3. Unable to change working arrangements
4. Emotional obligations
5. Prefer to care full-time
6. Provide additional disability care
7. Other (Specify)
8. (Don’t know)
9. (Refused)
*(CARERS NOT CURRENTLY WORKING) (AIFS W7)*

K13 If possible, would you like to have a job while still caring for
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?

1. Yes, a full-time job
2. Yes, a part-time job
3. No   GO TO PREK15
4. (Don’t know)    GO TO PREK15
5. (Refused)  GO TO PREK15

*(WOULD LIKE TO WORK) (AIFS W8)*

K14 What do you see as the main barrier to getting a job?

1. No alternative disability care arrangements available
2. Would be too disruptive to PERSON WITH DISABILITY
3. Difficulty in arranging working hours
4. Loss of skills from being out of workforce
5. Age
6. Cost of paying for disability care while at work
7. Other (Specify)
8. No difficulties expected
9. (Don’t know)
10. (Refused)

PREK15 IF MULTIPLE PERSON HOUSEHOLD (WITH ANY PERSONS OF WORKING AGE (15 TO 65) EXCLUDING RESPONDENT AND PERSON(S) CARED FOR (C4=CODES 1-8 AND C5 66>14)) CONTINUE. OTHERS GO TO PREK19

*(MULTIPLE PERSON HOUSEHOLD)*

K15 Now I would like to ask you about the employment of other current members of YOUR HOUSEHOLD.

1. Continue

*[LOOP K16-K18 FOR EACH HOUSEHOLD MEMBER AGED 15 OR MORE]*

*(MULTIPLE PERSON HOUSEHOLD) (AIFS FMJOB1)*

K16. Last week, did <insert name of first household member aged 15 or more> have a full-time or part-time job of any kind?

1. Yes, worked for payment or profit GO TO K18
2. Yes, but absent on holidays, on paid leave, on strike or temporarily stood down GO TO K18
3. Yes, unpaid work in a family business GO TO K18
4. Yes, other unpaid work  GO TO K18
5. Yes, on call but did not work GO TO K18
6. No
7. (Don’t know) RESTART LOOP OR GO TO K19
8. (Refused) RESTART LOOP OR GO TO K19

*(HOUSEHOLD MEMBER NOT CURRENTLY WORKING) (AIFS FMNOWK1)*

K17 Did <insert name of first household member aged 15 or more> actively look for work at any time in the last four weeks?

1. Was looking for full time work in the last 4 weeks
2. Was looking for part time work in the last 4 weeks
3. No, did not look for work in the last 4 weeks
4. No - retired
5. (Don’t know)
6. (Refused)
*(NOW RESTART LOOP OR GO TO K19)*

*(HOUSEHOLD MEMBER CURRENTLY WORKING) (AIFS FMHRSWK1)*

K18  About how many hours per week does <insert name of first household member aged 15 or more> usually work in all jobs, including paid or unpaid overtime?

1. Hours given (Specify___) (RANGE 0.5 TO 130.0)
2. (Don’t know)
3. (Refused)

*[CLOSE LOOP]*

PREK19 IF MULTIPLE PERSON HOUSEHOLD (WITH ANY PERSONS OF WORKING AGE (15 PLUS) EXCLUDING RESPONDENT AND PERSON(S) CARED FOR (C4=CODES 1-8 AND C5>14)) CONTINUE. OTHERS GO TO L1

*(MULTIPLE PERSON HOUSEHOLD WITH MEMBERS AGED 15 OR MORE) (AIFS W12)*

K19  (Besides yourself) Did any members of your current household have to give up paid work altogether to care for

<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>

1. Yes
2. No  GO TO L1
3. (Don’t know)  GO TO L1
4. (Refused)  GO TO L1

*(HOUSEHOLD MEMBER HAD TO GIVE UP PAID WORK)*

K20  Could you please tell me who had to give up paid work altogether to care for

<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?

(MULTIPLES ACCEPTED)

1. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_1 IF C6>14) NUMBER ONE
2. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_2 IF C6>14) NUMBER TWO
3. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_3 IF C6>14) NUMBER THREE
4. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_4 IF C6>14) NUMBER FOUR
5. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_5 IF C6>14) NUMBER FIVE
6. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_6 IF C6>14) NUMBER SIX
7. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_7 IF C6>14) NUMBER SEVEN
8. NAME OF HOUSEHOLD MEMBER AGED 15 OR MORE (insert name given at C5_8 IF C6>14) NUMBER EIGHT
9. (Refused)
What was the MAIN reason <insert name from K20> needed to leave their job to care for
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>

(INTELLIGENT NOTE: If respondent answers "Aside from <PWD>'s health, what circumstances led them to give up work?")

1. No alternative care arrangements available
2. Financial considerations/cost of alternative care arrangements
3. Unable to change working arrangements
4. Emotional obligations
5. Prefer to care full-time
6. Provide additional care
7. Other (specify)
8. (Don't know)
9. (Refused)
**L. Financial issues**

*(ALL) (AIFS CGINCOME)*

L1 And now for a couple of questions related to finances.....

What is YOUR GROSS PERSONAL income before tax or anything else is taken out? Please include income from all sources, including wages, investments, and governments pensions and benefits.

IF NECESSARY: You can tell me per week, fortnight, month or year

1. Amount given (Specify_____)(LIKELY RANGE 0.00 - 150,000.00)
2. (Don’t know) GO TO L3
3. (Refused) GO TO L3

*(GAVE AMOUNT IN L1) (AIFS CPERIOD)*

L2 What period does that cover?

1. A week
2. Fortnight
3. Four weeks
4. Calender month
5. Year
6. Other (Specify)
7. (Don’t know)
8. (Refused)

*PROGRAMMER NOTE: Please insert a check for data entered in L1 and L2, for example “you have entered $400 per week, is that correct?”*

1. Yes
2. No GO BACK TO L1 AND L2 TO FIX UP ERROR

PREL3 IF DON’T KNOW OR REFUSED INCOME (L1=CODES 2 OR 3) CONTINUE. OTHERS GO TO PREL4

*(REFUSED OR DK INCOME) (AIFS CGINCREF)*

L3 If you don’t want to give an exact amount, can you give me an indication of your annual income using these categories? (AID AS NECESSARY BY READING WEEKLY AMOUNTS)

1. Negative income (loss)
2. Nil income
3. $1-$2,599 per year ($1-$49 per week)
4. $2,600-$5,199 per year ($50-$99 per week)
5. $5,200-$10,399 per year ($100-$199 per week)
6. $10,400-$15,599 per year ($200-$299 per week)
7. $15,600-$20,799 per year ($300-$399 per week)
8. $20,800-$25,999 per year ($400-$499 per week)
9. $26,000-$31,199 per year ($500-$599 per week)
10. $31,200-$36,399 per year ($600-$699 per week)
11. $36,400-$41,599 per year ($700-$799 per week)
12. $41,600-$51,999 per year ($800-$999 per week)
13. $52,000-$77,999 per year ($1000-$1499 per week)
14. $78,000-$103,999 per year ($1500-$1999 per week)
15. $104,00-$114,399 per year ($2000-$2199 per week)
16. $114,400-$124,799 per year ($2200-$2399 per week)
17. $124,800 or more per year ($2,400 or more per week)
18. (Don’t know)
19. (Refused)
PREL4 IF HAVE OTHER HOUSEHOLD MEMBERS AGED 15 OR MORE (C6>14) CONTINUE.
OTHERS GO TO L7

*(HAS MULTIPLE HOUSEHOLD MEMBERS AGED 15 OR MORE) (AIFS FAMINC)
L4 What is YOUR HOUSEHOLDS GROSS income before tax or anything else is taken out.
Please include income from all sources, including wages, investments, and governments
pensions and benefits.

IF NECESSARY: You can tell me per week, fortnight, month or year

1. Amount given (Specify) (LIKELY RANGE 0.00 - 150,000.00)
2. (Don’t know) GO TO L6
3. (Refused) GO TO L6

*(GAVE A RESPONSE FOR L4) (AIFS FPERIOD)
L5 What period does that cover?

1. A week
2. Fortnight
3. Four weeks
4. Calendar month
5. Year
6. Other (specify)
7. (Don’t know)
8. (Refused)

*PROGRAMMER NOTE: Please insert a check for data entered in L4 and L5, for example “you have
entered $400 per week, is that correct?”

3. Yes
4. No GO BACK TO L4 AND L5 TO FIX UP ERROR

PREL6 IF DON’T KNOW OR REFUSED HOUSEHOLD INCOME (L2=CODES 2 OR 3) CONTINUE.
OTHERS GO TO L7

*(REFUSED OR DK HOUSEHOLD’S INCOME) (AIFS FAMINCREF)
L6 If you don’t want to give an exact amount, can you give me an indication of your household’s
annual income using these categories? (AID AS NECESSARY BY READING WEEKLY
AMOUNTS)

1. Negative income (loss)
2. Nil income
3. $1-$2,599 per year ($1-$49 per week)
4. $2,600-$5,199 per year ($50-$99 per week)
5. $5,200-$10,399 per year ($100-$199 per week)
6. $10,400-$15,599 per year ($200-$299 per week)
7. $15,600-$20,799 per year ($300-$399 per week)
8. $20,800-$25,999 per year ($400-$499 per week)
9. $26,000-$31,199 per year ($500-$599 per week)
10. $31,200-$36,399 per year ($600-$699 per week)
11. $36,400-$41,599 per year ($700-$799 per week)
12. $41,600-$51,999 per year ($800-$999 per week)
13. $52,000-$77,999 per year ($1000-$1499 per week)
14. $78,000-$103,999 per year ($1500-$1999 per week)
15. $104,00-$114,399 per year ($2000-$2199 per week)
16. $114,400-$124,799 per year ($2200-$2399 per week)
17. $124,800 or more per year ($2,400 or more per week)
18. (Don’t know)
19. (Refused)
L7 Since January this year, did any of the following happen to your family BECAUSE OF A SHORTAGE OF MONEY?

(STATEMENTS)
   a) Could not pay electricity, gas or telephone bills on time
   b) Could not pay the mortgage or rent on time
   c) Pawned or sold something
   d) Asked for financial help from friends or family

(RESPONSE FRAME)
   1. Yes
   2. No
   3. (Don’t know)
   4. (Refused)
*(ALL) (AIFS OPEN1)
M1  To finish we have a couple of final questions for you. What are the biggest challenges and the biggest rewards for your family caring for
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?

1. Continue

M1a  Firstly the challenges … (PROBE FOR A COMPLETE ANSWER)

1. None / can't think of any
2. Challenges given (specify)
3. (Don't know)
4. (Refused)

M1a  And secondly the rewards … (PROBE FOR A COMPLETE ANSWER)

1. None / can't think of any
2. Rewards given (specify)
3. (Don't know)
4. (Refused)

(ALL) (AIFS OPEN2)
M2  And finally what advice would you give to other families about coping with caring for someone like
<insert name from A3_1>
<insert name from A3_2>
<insert name from A3_3>?

1. No / none / nothing
2. Response given (specify)
3. (Don't know)
4. (Refused)

*(ALL)
CLOSE Thank you <insert name of carer from sample file> for answering these questions.

Researchers at the Australian Institute of Family Studies are very interested in finding out more about families in your situation. Would it be ok to call you again to see if you are available to participate in future research? IF NECESSARY: Regardless of whether you agree or not to be recontacted, please be assured that your government payments will be unaffected by your participation in this survey.

Do you agree for researchers at the Australian Institute of Family Studies to contact you again to invite you to participate in other research projects?

1. Yes
2. No  GO TO END

*(INTERESTED IN BEING RECONTACTED)
REC2  What’s the best phone number to contact you on?

CONFIRM NAME AND TELEPHONE CONTACT DETAILS

END  If there are any issues you would like to talk further with someone about, you may want to call the Carer Resource Centre. The toll-free number is: 1800 242 636. Once again, on behalf of the Australian Institute of Family Studies and the Social Research Centre, thanks for your time.
*(INTERVIEWER TO ENTER ONCE INTERVIEW IS COMPLETE)*

**INT1** Type of interview

1. Normal  GO TO DECLARATION
2. LOTE
3. Refusal Conversion  GO TO DECLARATION

*(.INTERVIEWER TO ENTER ONCE INTERVIEW IS COMPLETE)*

**LANG** Which language was this interview mainly completed in

1. Arabic
2. Cantonese
3. Greek
4. Italian
5. Mandarin
6. Vietnamese

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**Interviewer Declaration**

I certify that this is a true, accurate and complete interview, conducted in accordance with the briefing instructions, the IQCA standards and the MRSA Code of Professional Behaviour (ICC/Esomar). I will not disclose to any other person the content of this questionnaire or any other information relating to the project.

Interviewer name: 

Interviewer I.D: 

Signed: 

Date: 

---
*(REFUSED)*

RR1 OK, that’s fine, no problem, but could you just tell me the main reason you do not want to participate, because that’s important information for us?

1. No comment / just hung up
2. Too busy
3. Not interested
4. Too personal / intrusive
5. Don’t like subject matter
6. Brochure put me off
7. Don’t believe surveys are confidential / privacy concerns
8. Silent number
9. Don’t trust surveys / government
10. Never do surveys
11. 25 minutes is too long
12. Get too many calls for surveys / telemarketing
13. Ill health / disability
14. Too old / too frail
15. Not a residential number (business, etc) (CODE AS NOT A RESIDENTIAL NUMBER)
16. Language difficulty (CODE AS LANGUAGE DIFFICULTY NO FOLLOW UP)
17. Going away / moving house (CODE AS AWAY DURATION)
18. Asked to be taken off list (add to do not call register)
19. Other (Specify)

*(REFUSED)*

RR2 RECORD RE–CONTACT TYPE

1. Definitely don’t call back
2. Possible conversion

TERMINATION SCRIPT 1
Thanks anyway, but for this study we need to talk to people who are receiving a carer allowance and / or carer payment.

TERMINATION SCRIPT 2
Thanks anyway, but to continue with the study we need to collect details of how many people you care for.