A1. Enter serial number from contact sheet

A2. Enter checksum from contact sheet

A3. INTERVIEWER CODE WHO GAVE CONSENT
   - Individual (respondent)
   - Support Person

IF CONSENT GIVEN BY SUPPORT PERSON AT A3 (THEY MUST BE PRESENT AT THE INTERVIEW IN THIS CASE) CODE A4.

(nb IF INDIVIDUAL GAVE CONSENT WE ASSUME MAY BE ABLE TO ANSWER SOME QUESTIONS)

A4. INTERVIEWER CODE WHETHER individual MAY be able to answer at least some simple yes/no questions for themselves, or whether their learning difficulty is so profound that they cannot respond for themselves at all. You should have been able to assess this whilst going through the consent procedure

IF UNSURE CODE 1 AND SEE HOW GET ON WITH ASSESSMENT QUESTIONS
   - YES - Individual may be able to answer some questions – INDIVIDUAL AND/OR SUPPORT PERSON - GO TO ASSESSMENT
   - NO - Individual unable to respond for themselves – SUPPORT PERSON ONLY – GO TO MAIN SURVEY

IF INDIVIDUAL GAVE CONSENT AT A3 ASK A5 TO A7

A5. INTERVIEWER CODE WHETHER support person is present at interview?.
   IF NO – check with individual if they would like someone present and if necessary find someone (and code yes) before going on.
   - Yes – GO TO A6
   - No – (INDIVIDUAL ONLY – GO TO ASSESSMENT)

IF YES AT A4

A6. Enter name of support person present, as individual refers to them, for substitution in A7

IF SUPPORT PERSON PRESENT AT A5

A7. In a minute we want to ask you some questions. BUT Is it ok if (name of support person here) answers some questions as well?

   - Yes – ok for support person to take part – INDIVIDUAL AND/OR SUPPORT PERSON – GO TO ASSESSMENT
   - No – does not want support person to take part – INDIVIDUAL ONLY – GO TO ASSESSMENT

nb. FROM THESE QUESTIONS WILL KNOW WHO RESPONDENT WILL PROBABLY BE (see underlined outcomes alongside questions)
INTERVIEWER NOTE ON SCREEN – (1 OF 4 POSSIBLE OUTCOMES AT THIS STAGE AS BELOW):

1. IF INDIVIDUAL DEEMED UNABLE TO RESPOND AT A4: The support person will be answering all of the questions. However, the individual should be present, and you should pay attention to them and make sure that if they want to contribute in some way they can. – GO ON TO MAIN SURVEY

2. IF NO AT A5: As only the individual is present go on to use SHEET 1 to assess which questions they will be able to answer.

3. IF NO AT A7 – the individual does not want the support person to answer any questions and has been deemed capable of informed consent. You should explain to the support person that you want the individual to answer all of the questions for themselves and then go on to use SHEET 1 to assess which questions the individual will be able to answer without any assistance.

4. IF ABLE TO ANSWER SOME QUESTIONS AT A4 OR HAPPY FOR SUPPORT PERSON TO STAY AT A7 – Both the individual and support person will be answering some questions. Use SHEET 1 to assess which questions the individual will be able to answer without any assistance

IF OUTCOME 2, 3 OR 4 ABOVE [equates to A4(1) or A3(1)]: ASSESSMENT IS DONE ON PAPER USING SHEET 1. OUTCOME ENTERED AT NEXT QUESTION:

A8. DO NOT READ OUT. ENTER INDIVIDUAL ASSESSMENT INTO CAPI

- Levels 1 and 2
- Level 1 only
- Carer only – i.e. Neither level

INTERVIEWER NOTE ON SCREEN – NOTE ON WHO WILL GET LEVEL 1 AND 2 QUESTIONS

A. IF [NO AT A7 OR NO AT A5] AND A8 = CARER ONLY – terminate interview - individual unable to respond and support person not present or not wanted by individual. (NOTE: FOR PANEL – we hope this will not happen often – it assumes the individual is judged able to give informed consent, does not want the support person to answer ANY questions (or SP is not present at all), but was then not able to answer the questions consistently at the assessment exercise)

B. IF [YES AT A7 OR YES AT A4], AND A8 = CARER ONLY The individual is unlikely to be able to answer any questions without help. You should address all level 1 and level 2 questions to the individual, but the support person will need to help with the answer. – GO ON TO MAIN SURVEY

C. IF [NO AT A7 OR NO AT A5] AND A8 = LEVEL 1 OR LEVEL 1 & 2 – All questions will be put to the individual – if the support person is present and tries to answer for them at any point explain you want the individual to answer for themselves. – GO ON TO MAIN SURVEY
D. IF [YES AT A7 OR YES AT A4] AND A8 = LEVEL 1 OR LEVEL 1 & 2 – Some questions will go to the individual alone and for some they will need help from the support person. Follow the instructions on your screen. If the individual gets tired during the questionnaire and does not want to carry on you can switch questioning to the support person and should note this at the regular questions asking who is answering the questions. – GO ON TO MAIN SURVEY

E. If NO at A4 – All questions will be put to the support person, since the individual is unable to communicate.

INSTRUCTIONS TO QUANQUEST PROGRAMMER ON HOW TO FILTER AND INTRODUCE LEVEL 1, 2 AND 3 QUESTIONS. NB PUT ALL TEXT IN CAPITALS, AND PUT “DO NOT READ OUT” AT START OF EACH TEXT ITEM.

LEVEL 1 – these will go to all respondents (nb excludes terminated interviews). Need text items (same) before each blocks of level 1 questions as follows:

A IF [A4=NO] – text item should read “LEVEL 1 QUESTIONS”

B IF [(A7=YES OR A4=YES) AND (A8=CARER ONLY)] text item should read: “Level 1 questions – individual will need help from support person with these questions. If they are unable or unwilling to continue you may put these questions to the support person instead.”

C IF [(A7=NO OR A5=NO) AND (A8 = LEVEL 1 OR A8=LEVEL 1 & 2)] text item should read:
“LEVEL 1 questions – to be answered by individual. If individual is unwilling or unable to continue the interview you will have terminate the interview and skip to the end to collect address details”

D IF [(A7=YES OR A4=YES) AND (A8 = LEVEL 1 OR A8=LEVEL 1 & 2)] text item should read:
“Level 1 questions – to be answered by individual. If individual is unwilling or unable to continue you may put the questions to the support person instead.

LEVEL 2 - Each set of these items should be within the following skip filter:

IF [A4=NO] OR [A7=YES OR A4=YES] OR [(A7=NO OR A5=NO) AND (A8=LEVEL 1 & 2)]

Within this filter the set of level 2 questions should then be introduced with the following text items:

A IF [A4=NO] – text item should read “level 2 questions”

B IF A7=YES OR A4=YES AND (A8=CARER ONLY OR A8=LEVEL 1 ONLY)] text item should read:
“Level 2 questions – individual will need help from support person with these questions. If they are unable or unwilling to continue you may put these questions to the support person instead.”

C IF [(A7=NO OR A5=NO) AND (A8=LEVEL 1 & 2)] text item should read:
“Level 2 questions – to be answered by individual. If individual is unwilling or unable to continue the interview you will have terminate the interview and skip to the end to collect address details”

D IF [(A7=YES OR A4=YES) AND (A8=LEVEL 1 & 2)] text item should read:
“Level 2 questions – to be answered by individual. If individual is unwilling or unable to continue you may put the questions to the support person instead.
**LEVEL 3** – these questions will only go to support persons. Each set of these items should go within the following skip filter:

IF [A4=NO] OR [A7=YES OR A4=YES]; Text item should be the same for all: “**Level 3** questions – ONLY to be answered by **support person**”

On every question we need the following response options

- Unable to answer/unclear response
- Refused
NOTE – LEVEL 2 QUESTIONS ARE IN ITALICS

PROGRAMMER NOTE – FOR THESE FIRST FOUR QUESTIONS DO NOT USE STANDARD LEVEL 1/LEVEL 2 TEXT – USE TEXT GIVEN BELOW INSTEAD. PLEASE USE STANDARD LEVEL 2 SKIP FILTER.

Q1. Do you live in the countryside or in a town?
   - Town
   - Something in between
   - Countryside
   - Unable to answer/unclear response (this response will be available for all questions)

Q2. Who do you live with?
   - Parents
   - Partner/spouse
   - Other family
   - Friends / someone other than family (eg other residents)
   - Paid support worker
   - Live alone
   - Unable to answer/unclear response

LEVEL 2 FILTER AS NORMAL.

LEVEL 2 TEXT:
IF [A4=NO] text item should read “Level 2 questions”
IF A7=YES OR A4=YES AND (A8=CARER ONLY) text item should read:
   “Level 2 questions – Address to individual but will need help from support person”
IF [(A7=NO OR A5=NO) AND (A8 = LEVEL 1 OR A8=LEVEL 1 & 2)] text item should read:
   “Level 2 questions – answers may be copied from SHEET 1 from assessment stage”
IF [(A7=YES OR A4=YES) AND (A8=LEVEL 1 & 2)] text item should read:
   “Level 2 questions – answers may be copied from SHEET 1 from assessment stage”
Q3. Do you live in a caravan or in a flat or in a house? (amended census)
- House/bungalow
- Flat/apartment
- Caravan/mobile home
- (Room in Residential home/hospital)
- Unable to answer/unclear response

Q4. About how long have you lived there
- All your life
- Longer than 10 years
- Longer than 5 years
- Less than 5 years
- Unable to answer/unclear response

PERSONAL DEMOGRAPHICS

PROGRAMMER NOTE – ALL REMAINING LEVEL 1, 2 AND 3 QUESTIONS SHOULD HAVE STANDARD FILTERS AND TEXT AS DESCRIBED ON PAGE 3. LEVEL 2 QUESTIONS ARE IN ITALICS

Before we start, it would be helpful to know just a little more about you. So, first of all,

SHOWCARD 1.

Q5. How do you feel about your life at the moment? Please point to the face. (SP)

- Very happy
- Quite happy
- Sometimes happy, sometimes unhappy
- Mostly unhappy

Q6. How old are you?
Q7. Code male / female
Q8. Are you married or living with a partner? IF NO, have you ever been married?
- Single / never married
- Married / living with partner
- Widowed / divorced / separated
SHOWCARD 2.

Q9. Which ethnic group do you consider you belong to? ONS
- White (British) / other white
- Asian or Asian British (Indian, Pakistani, Bangladeshi, other Asian)
- Black or Black British (Caribbean, African, other black)
- Chinese or other ethnic group

Q10. Is English your main language?
- Yes
- No
- Unable to speak

IF SUPPORT PERSON PRESENT – ASK THEM (LEVEL 3)

Q11. What is your relationship to (name of individual). Are you a … (L3) (MULTICODE)
- Parent
- Partner
- Other family member
- Friend
- Paid support worker
- Independent advocate
- Other

IF SUPPORT PERSON PRESENT (A3 = SUPPORT PERSON or A5=YES)

Q12. INTERVIEWER TO CODE - Who answered majority of questions in this section
- Individual alone
- Support worker alone
- Individual and support worker together

FURTHER QUESTIONS ON HOUSING/HOUSEHOLD

A) QUESTIONS ABOUT WHERE THEY LIVE AND WHO THEY LIVE WITH

SHOWCARD 3.
Next, we’re going to talk about where you live and (IF NOT ALONE AT Q2) who you live with

Q13. INTERVIEWER TO CODE - Does the respondent live in … – Probe if necessary
- In fully private household – (with support person or independently)
- In supported housing
- In residential care
- Long stay hospital or retained NHS bed
IF SUPPORTED HOUSING FIND OUT NAME FOR LATER
IF FULLY RESIDENTIAL FIND OUT NAME OF ACCOMMODATION AND ASK:

Q14. Who runs (name of residential accommodation)? (Probe if necessary)
- NHS
- Private
- Charity/voluntary organisation

IF FULLY PRIVATE OR SUPPORTED ASK
Q15. Is the place where you live owned or rented?
- Owned (fully or with a mortgage)
- Rented
- Live rent free

IF RENTED
Q16. Who is it rented from?

NOTE Housing Association includes Co-operative, Charitable Trust, Registered Social Landlord
- Council or Housing Association
- Private landlord

IF NOT ALONE AT Q2 AND NOT IN RESIDENTIAL ACCOMMODATION
Q17. Including yourself, how many people live here?
- Two
- Three
- Four
- Five
- Six
- Seven – ten
- Eleven – twenty
- Over twenty

SHOWCARD 4.
Q18. Did you choose or pick the people you live with? (CIP)
IF YES – DID YOU HAVE ANY HELP CHOOSING?
- No – someone else chose
- Yes – chose with help
- Yes – chose alone
- ONLY IF SAID SPONTANEOUSLY - Still live at home with parents
- Unable to answer/unclear response
IF LIVE WITH PARENTS AT Q2
Q19. You said you live with your parent(s). About how old are they?
(If ages very different take age of youngest)
• Under 45
• 46-54
• 55-64
• 65-74
• 75+

IF SUPPORT PERSON PRESENT
Q20. Interviewer to code - Who answered majority of level 1 questions on where the respondent lives and who they live with
• Individual alone
• Support worker alone
• Individual and support worker together

Q21. Interviewer to code - Who answered majority of level 2 questions on where the respondent lives and who they live with
• Individual alone
• Support worker alone
• Individual and support worker together

B) DETAILS OF WHERE THE RESPONDENT LIVES

ASK ALL. SHOWCARD 4
Q22. Did you choose or pick the place where you live? (CIP)
   • If yes – Did you have any help choosing?
     • No – someone else chose
     • Yes – chose with help
     • Yes – chose alone
     • Only if said spontaneously Still live at home with parents – N/A
     • Unable to answer/unclear response

SHOWCARD 5.
Q23. Do you like living there?
Q24. If no – What don’t you like about it?
Q25. Is it usually warm enough where you live?
Q26. Is there enough room for everyone where you live? (If necessary - Is it big enough?)
Q27. Do you feel safe when you are at home at night? (SP)
Q28. And do you feel safe in the area where you live? (SP)

IF NOT IN PRIVATE HOUSEHOLD WITH PARENTS/PARTNER/FAMILY ASK NEXT SET OF QUESTIONS:
SHOWCARD 6.
Q29. Do you share a bathroom with other people? (SP)

SHOWCARD 7.
Q30. IF YES – Do you like sharing a bathroom? (SP)

SHOWCARD 8.
Q31. Do you share a kitchen with other people? (SP)

SHOWCARD 9.
Q32. IF YES – Do you like sharing a kitchen? (SP)

SHOWCARD 10. Next two questions
Q33. Are there any rules about what you can do where you live? (if necessary – are there things you are not allowed to do where you live) (SP)

SHOWCARD 11.
Q34. IF YES – Are you happy with these rules? (SP)

IF SUPPORT PERSON PRESENT
Q35. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON WHERE THE RESPONDENT LIVES
   • Individual alone
   • Support worker alone
   • Individual and support worker together

C) HELP AT HOME

IF NOT IN RESIDENTIAL ACCOMODATION ASK NEXT SET OF QUESTIONS:

SHOWCARD 12.
Q36. Does someone help you at home? (i.e. support person)

IF NO ONE HELPS
Q37. Would you like someone to help you at home?

IF SOMEONE HELPS
SHOWCARD 13.
Q38. Did you choose or pick who helps you? (CIP)
Q39. Who helps you? Is it a relative or friend or a paid support person?

CAN MULTICODE
   • Relative (parent/partner/other family)
   • Friend
   • Paid/ professional support person
FOR EACH OF PROFESSIONAL AND NON-PROFESSIONAL (if used)

Q40. How often do you get help from your /relatives and (or) friends/paid support person/ ?

NOTE – IF more than one of each type, try to get time in total helped by relatives etc.
- Live in same place
- Every day (not resident)
- Most days
- A few times a week
- Once a week
- Less often

IF LIVED IN CURRENT ACCOMMODATION LESS THAN 5 YEARS AT Q4

Q41. Did you move into your home in the last 2 years?

IF LIVED IN CURRENT ACCOMMODATION 10 YEARS OR LESS AT Q4

Q42. Before you moved to where you live now, where did you used to live? (Probe to find out what type of accommodation it was) (if necessary – where did you live before?)
- In fully private household – (with support person/friends or family or independently
- In supported housing
- In residential care
- Long stay hospital or retained NHS bed

IF IN SUPPORTED OR RESIDENTIAL HOUSING NOW, AND MOVED THERE IN LAST 2 YEARS

Q43. Did you get any help from the people at (XXX – name collected earlier) before you moved there? (SP)

LEVEL 3 QUESTIONS

Q44. Would you say X’s accommodation is suitable for them given his/her needs? (adapted SEH)

Q45. If Q41 = NO, In what way is it not suitable? (Open Ended - FOR ODPM)

Q46. How would you describe the physical quality of their accommodation
- Good – no major improvements needed
- Ok – some upgrading needed
- Poor – major upgrading needed

IF SUPPORT PERSON PRESENT

Q47. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON HELP AT HOME
- Individual alone
- Support worker alone
- Individual and support worker together
Q48. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON HELP AT HOME

- Individual alone
- Support worker alone
- Individual and support worker together

LEVEL OF SUPPORT NEEDED/PRIVACY

A) LEVEL OF SUPPORT

All of us need help at times to do things that we find difficult. I now want to ask you some questions about how much help you usually need to do different things. Looking at this card …

SHOWCARD 14. a-c AND WHITE CARD A

Q49. I want you to tell me for each thing whether you can do it on your own, or you need a bit of help, a lot of help or someone to do it for you. So first of all …

- Getting dressed in the morning
- Putting on a pair of shoes
- Having a shower or a bath
- Ordering something to eat or drink at a cafe
- Drinking a cup of tea
- Washing your clothes
- Making a sandwich
- Filling in a form (for example if you were applying for a job)
- Finding out what is on the TV tonight
- Paying money into your bank or Post Office
- Making an appointment (for example to see your doctor) (SP)

NOTE – MAY NOT APPLY TO ALL EG NO TV – ADD NOT APPLICABLE - BRIEF CAREFULLY TO ENSURE NOT USED TO MEAN “CAN DO IT ALONE”

FOR EACH OF THE ITEMS WHERE THEY SAID THEY NEED A BIT OF HELP OR A LOT OF HELP/ SOMEONE TO DO IT FOR THEM:

Q50. And do you get any help with (SP)

- Getting dressed in the morning
- Putting on a pair of shoes
- Having a shower or a bath
- Ordering something to eat or drink at a cafe
- Drinking a cup of tea
- Washing your clothes
- Making a sandwich
- Filling in a form (for example if you were applying for a job)
- Finding out what is on the TV tonight
- Paying money into your bank or Post Office
- Making an appointment (for example to see your doctor) (SP)
IF SUPPORT PERSON PRESENT
Q51. **INTERVIEWER TO CODE** - Who answered majority of level 2 questions ON LEVEL OF SUPPORT
   - Individual alone
   - Support worker alone
   - Individual and support worker together

B) PRIVACY

IF NOT IN RESIDENTIAL CARE
SHOWCARD 15.
Q52. **PRIVACY ISSUES** - Does anyone come into your home without asking— or when you don’t want them to? (Amended CIP)

ASK ALL
SHOWCARD 16.
Q53. Does anyone come into your room without asking or when you don’t want them to? (CIP)

IF YES
Q54. Who does this?
   - Paid support person/carer/staff at residential home
   - Someone else you live with
   - Family or friend you DON’T live with
   - Other (SPECIFY)

SHOWCARD 17.
Q55. When people come to visit can you be alone with them or does someone have to be with you? (CIP)?

SHOWCARD 18.
Q56. Does anyone ever open your letters without asking? (amended CIP)

SHOWCARD 19.
Q57. Can you be by yourself as much as you want to? (CIP)
   - Yes
   - No
   - Never want to be alone

IF SUPPORT PERSON PRESENT
Q58. **INTERVIEWER TO CODE** - Who answered majority of level 1 questions ON PRIVACY
   - Individual alone
   - Support worker alone
   - Individual and support worker together
Q59. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON PRIVACY
- Individual alone
- Support worker alone
- Individual and support worker together

C) HELP WITH HOUSING

ASK ALL
SHOWCARD 20.
Q60. If you needed help with your housing, where would you go?
- Paid help/professional support person / staff in residential home
- Friends/ family
- Social Services
- Housing department/ Local Housing Authority
- Citizens Advice Bureau/ Local Advice agency
- Landlord
- Other (specify)

Q61. Have you ever had any help with your housing?
Q62. Who from?
- Paid help/professional support person / staff in residential home
- Friends/ family
- Social Services
- Housing department/ Local Housing Authority
- Citizens Advice Bureau/ Local Advice agency
- Landlord
- Other (specify)

FOR PAID HELP/HOUSING DEPARTMENT/LOCAL HOUSING AUTHORITY AND SOCIAL SERVICES IF USED ASK

SHOWCARD 21.
Q63. How happy were you with the help you received from…?
- Very happy
- Quite happy
- Not happy

IF NOT MENTIONED ASK
Q64. Did you know that there are people who can you can go to for information about housing?
IF SUPPORT PERSON PRESENT
Q65. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON HELP WITH HOUSING

- Individual alone
- Support worker alone
- Individual and support worker together

CARING COMMITMENTS

IF LIVE WITH ANYONE AND NOT IN RESIDENTIAL CARE

A) CARING FOR AN ADULT

SHOWCARD 22.
Q66. Does anyone live with you who is old, sick or disabled?

IF YES
Q67. Do you have to look after them? (Amended GHS/HSE)

IF YES
Q68. So who is it you look after?

- Parent
- Partner
- Child
- Other relative
- Friend

SHOWCARD 23. A&B
Q69. What do you do to help them?

- Cooking
- Washing / ironing
- Cleaning
- Shopping
- Personal care e.g. personal hygiene, taking to the toilet etc

SHOWCARD 24.
Q70. Does anyone help you look after them?

Q71. Who helps you?

- Parent
- Partner
- Child
- Other relative
- Friend
- Paid help / professional support person/staff at residential home
- Other

SHOWCARD 25.
Q72. How happy are you with the help you get?
   - Very happy
   - Quite happy
   - Not happy

Q73. Would you like (more) help looking after them?

Q74. If you needed help, who would you turn to?
   - Parent
   - Partner
   - Child
   - Other relative
   - Friend
   - Paid help / professional support person/staff at residential home
   - Social services
   - Other

IF SUPPORT PERSON PRESENT
Q75. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON CARING FOR AN ADULT
   - Individual alone
   - Support worker alone
   - Individual and support worker together

Q76. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON CARING FOR AN ADULT
   - Individual alone
   - Support worker alone
   - Individual and support worker together

B) CARING FOR CHILDREN
SHOWCARD 26.
Q77. Do you have any children?
Q78. IF YES How many?
   IF HAVE OWN CHILDREN
Q79. Do you look after your children/ child?
SHOWCARD 27.
Q80. Does anyone help you look after them?
Q81. Who?
- Parent
- Partner
- Child
- Other relative
- Friend
- Paid help / professional support person/staff at residential home
- Social services
- Other

SHOWCARD 28.

Q82. How happy are you with the help you receive?
- Very happy
- Quite happy
- Not happy

Q83. Would you like (more) help looking after your child / children?

Q84. If you needed help, who would you turn to?
- Parent
- Partner
- Child
- Other relative
- Friend
- Paid help / professional support person/staff at residential home
- Social services
- Other

IF SUPPORT PERSON PRESENT

Q85. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON CARING FOR CHILDREN
- Individual alone
- Support worker alone
- Individual and support worker together

Q86. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON CARING FOR CHILDREN
- Individual alone
- Support worker alone
- Individual and support worker together
INCOME

A) CONTROL OVER FINANCES

I am now going to ask you some questions about money.

SHOWCARD 29. a,b&c
Q87. Sometimes, when money is tight, people have to go without things. In the last year have you always had enough money for XXX when you wanted it/them? (Amended PSE)

IF SAY NEVER WANTED/BOUGHT CODE AS “YES – HAS ENOUGH”
  • New Clothes
  • New Shoes
  • Food
  • Heating
  • Telephoning friends or family
  • Going out
  • Visits to the pub or a club
  • A hobby or sport
  • A holiday

SHOWCARD 30. (next two questions)
Q88. Do you choose how much money you can spend each week? (or does someone else decide how much money you can have?) (adapted from CIP)
Q89. Do you choose the things you buy with your money? (adapted from CIP)

SHOWCARD 31.
Q90. Do you have enough money to do the things you want to do? (or would you like more?)

SHOWCARD 32.
Q91. Does someone help you look after your money?
Q92. Who helps you?
  • Parent
  • Partner
  • Child
  • Other relative
  • Friend
  • Paid help / professional support person/staff at residential home
  • Social services
  • Other

Q93. Would you like any (more) help with looking after your money?
Q94. Who from?

- Parent
- Partner
- Child
- Other relative
- Friend
- Paid help / professional support person/staff at residential home
- Social services
- Other

IF SUPPORT PERSON PRESENT

Q95. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON FINANCES

- Individual alone
- Support worker alone
- Individual and support worker together

Q96. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON FINANCES

- Individual alone
- Support worker alone
- Individual and support worker together

B) BENEFITS

Q97. Do you receive any benefits?

Q98. IF YES And what benefits do you receive?

- Disability Living Allowance
- Severe disability allowance
- Income Support
- Incapacity Benefit
- Housing benefit
- Other

SHOWCARD 33.

Q99. Do you receive your benefits yourself or does someone else receive them for you?

NOTE – PROBE TO FIND OUT IF RECEIVE ALL OF BENEFITS OR IF SOMEONE ELSE GIVES THEM AN ALLOWANCE OUT OF IT – ONLY CODE YES IF THEY RECEIVE ALL OF THEIR OWN ALLOWANCE. NOTE - PAID INTO OWN ACCOUNT = RECEIVE SELF
IF SOME ONE ELSE RECEIVES

Q100. *Who gets your benefits for you?*
- Parent
- Partner
- Child
- Other relative
- Friend
- Paid help / professional support person/staff at residential home
- Social services
- Other

Q101. *Would you like to get the benefits yourself?*

SHOWCARD 34.

Q102. *Have you heard of Direct Payments? This is where you get money yourself and you buy the services you need with that money. This is instead of other people choosing things for you*

Q103. *Have you applied for Direct Payments*

Q104. *Do you get Direct Payments*

Level 3 question

Q105. *Can I just check whether (name of respondent) does receive all of their own benefits, or whether somebody else receives them and manages them on their behalf?*

IF SUPPORT PERSON PRESENT

Q106. INTERVIEWER TO CODE - *Who answered majority of level 1 questions ON BENEFITS*
- Individual alone
- Support worker alone
- Individual and support worker together

Q107. INTERVIEWER TO CODE - *Who answered majority of level 2 questions ON BENEFITS*
- Individual alone
- Support worker alone
- Individual and support worker together

**PAID EMPLOYMENT**

A) CURRENT EMPLOYMENT

“I am now going to ask you some questions about jobs and working”.

SHOWCARD 35.

Q108. *Do you have a job at the moment?*
IF NO JOB
Q109. *Why don’t you have a job?* (Open ended for pilot)

- ADD CODE – Unable to work (e.g. because of disability)

IF UNABLE TO WORK SKIP TO NEXT SECTION

IF NO JOB
Q110. Would you like a job?

IF WANTED A JOB ASK NEXT TWO QUESTIONS

Q111. *Are you worried that if you got a job you might lose some of your benefits?*

Q112. *Would you like a job even if it meant losing some of your benefits?*

IF HAVE A JOB
Q113. What job do you do?

SHOWCARD 36.
Q114. *How many hours a week do you usually work in this job?*

Q115. *Is this the number of hours you want to work?*

Q116. *IF NO – Would you like to work more hours or less hours?*

Q117. Do you like your job?

SHOWCARD 37.
Q118. Does anyone ever bully you at work?

Q119. Did you choose what job you would do? (amended CIP)

SHOWCARD 38.
Q120. Are you paid to do this job?

Q121. *Are you paid per hour you work, or are you paid for each shift, each time you work, each thing you do etc.*

Q122. *And how much are you usually paid each time/ paid per hour*

SHOWCARD 39.
Q123. *Is the money paid to you personally for you to choose what to do with it or is it paid to someone else for them to look after for you? NB PAID INTO OWN BANK ACCOUNT MEANS PAID DIRECTLY TO YOU*

Q124. *When you started working, did you lose any of your benefits?*

IF YES

Q125. *Did this cause you any problems?*

IF SUPPORT PERSON PRESENT
Q126. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON CURRENT EMPLOYMENT

- Individual alone
- Support worker alone
- Individual and support worker together
Q127. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON CURRENT EMPLOYMENT

- Individual alone
- Support worker alone
- Individual and support worker together

B) GETTING A JOB

“I am now going to ask you some questions about finding a job”

ASK ALL WHO WORK OR WANT TO WORK

Q128. Which of these have you heard of?

- The WORKSTEP programme?
- The Jobs – help programme? (DUMMY)
- The New Deal (for Disabled People)?
  YOUNG PEOPLE AGED UP TO 25
- Connexions service

FOR EACH HEARD OF

Q129. Have you used

- WORKSTEP
- Jobs help?
- New Deal
- Connexions?

FOR EACH USED

Q130. Are you happy with

- WORKSTEP?
- New Deal?
- Connexions?

ASK ALL WHO WORK OR WHO WANT TO WORK

SHOWCARD 40.

Q131. Have you been offered any training to help you take up a job?

ASK ONLY IF WORK

SHOWCARD 41.

Q132. IF WORK – Do you have someone who can help you out at work?

- Yes
- No
- Do not need help at work

ASK ALL WHO WORK OR WHO WANT TO WORK

Q133. IF WORK Did you get any help when you were looking for a job? IF LOOKING FOR WORK Do you get any help looking for a job?
Q134. *Who from?*

- Parent
- Partner
- Other relative
- Friend
- Paid Support person/Carer/staff at residential home
- Social Services
- WORKSTEP
- New Deal
- Connexions
- Job Centre
- Other (STATE)

**IF SUPPORT PERSON PRESENT**

Q135. *INTERVIEWER TO CODE - Who answered majority of level 1 questions ON GETTING A JOB*

- Individual alone
- Support worker alone
- Individual and support worker together

Q136. *INTERVIEWER TO CODE - Who answered majority of level 2 questions ON PAID GETTING A JOB*

- Individual alone
- Support worker alone
- Individual and support worker together

**EDUCATION/TRAINING**

**A) SCHOOL**

All under 25

SHOWCARD 42.

Q137. Do you still go to school or college? (amended census)

SHOWCARD 43.

Q138. Did/ do you go to an ordinary school or a special school?

*IF ORDINARY SCHOOL*

Q139. Did/ do you go to a special needs unit at your school, or were you in the main school?

*IF SPECIAL SCHOOL*

Q140. Was/ is this a special school for people with learning difficulties, or some other kind of special school?

- For people with learning difficulties
- For people with learning difficulties AND some other group
- Other (specify)
ASK ALL

SHOWCARD 44.
Q141. Did/ do you like it at school? (if necessary – On the whole did you like it?)

SHOWCARD 45.
Q142. Could you choose whether you went to an ordinary school or a special school?
Q143. Which would you have liked best? To go to an ordinary school or a special school?

SHOWCARD 46.
Q144. Did anyone ever bully you at school?
Q145. Do you have any qualifications or exams?

Q146. What have you got?
   • NVQs
   • GCSE / O Levels
   • A levels
   • Degree / HND
   • City and Guilds
   • Btec
   • Other

IF HAVE GCSE/O LEVELS
Q147. How many GCSE’s or O Levels have you got?
Q148. What is the highest grade you got at GCSE or O Level?
   • A* - G

IF HAVE A LEVELS
Q149. How many A Levels have you got?
Q150. What is the highest grade you got at A level?
   • A – E, N, U

IF SUPPORT PERSON PRESENT
Q151. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON SCHOOL
   • Individual alone
   • Support worker alone
   • Individual and support worker together

Q152. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON PAID SCHOOL
   • Individual alone
   • Support worker alone
   • Individual and support worker together
B) TRAINING

SHOWCARD 47.
Q153. Are you doing any courses or doing any training at the moment?
Q154. IF YES – is this at college, at work, at a day centre or somewhere else? (MULTICODE)
  • College
  • Work
  • Day centre
  • Elsewhere

Q155. What courses are you doing? (open)
Q156. IF NOT DOING COURSE Would you like to do a course or some training?
Q157. ASK ALL If you wanted to find out about doing a course or some training, who would you ask?
  • Partner
  • Child
  • Other relative
  • Friend
  • Paid support person/ Carer/ staff in residential home
  • At a college / place would get education / training
  • At the library
  • Social worker/ key worker
  • At the day centre
  • Other

IF SUPPORT PERSON PRESENT
Q158. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON TRAINING
  • Individual alone
  • Support worker alone
  • Individual and support worker together

Q159. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON TRAINING
  • Individual alone
  • Support worker alone
  • Individual and support worker together

HEALTH

A) GENERAL HEALTH

SHOWCARD 48.
I am now going to ask you some questions about your health – things like whether you are ever ill, whether you keep fit and so on …
SHOWCARD 49.

Q160. In the last year would you say your health was very good, fairly good or not good (amended census)

Q161. Do you have a illness or physical disability that you have had for a long time?

IF YES

Q162. What is this?

- Physical disability
- Difficulty seeing
- Difficulty hearing
- Difficulty speaking
- Mental Health problem
- Epilepsy
- Autism
- Other

Q163. Have special changes been made to where you live because of your problem?

SHOWCARD 50. (for next four questions)

All of us feel a bit unhappy or worried at times. (amended PSE)

Q164. Do you ever feel sad or worried? (IF YES – Is that a lot or just sometimes)

- A lot
- Sometimes
- Never

Q165. Do you ever feel left out of things? (IF YES – Is that a lot or just sometimes)

- A lot
- Sometimes
- Never

Q166. Do you ever feel helpless? (IF YES – Is that a lot or just sometimes)

- A lot
- Sometimes
- Never

Q167. Do you ever feel confident about yourself? (IF YES – Is that a lot or just sometimes) (NOTE – if necessary use “sure of yourself”)

- A lot
- Sometimes
- Never

SHOWCARD 51.

Q168. Do you have someone you can ask for help if you are feeling a bit down or sad ... adapted PSE).

SHOWCARD 52.

Q169. Do you smoke cigarettes nowadays (HSE)
SHOWCARD 53.
Q170. Do you ever do any exercise these days that makes you out of breath and sweaty?
Q171. How many days a week do you do this?

IF SUPPORT PERSON PRESENT
Q172. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON GENERAL HEALTH
   • Individual alone
   • Support worker alone
   • Individual and support worker together

Q173. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON GENERAL HEALTH
   • Individual alone
   • Support worker alone
   • Individual and support worker together

B) MEDICAL TREATMENT
Q174. If you were ill, who would you go to for help?
   • Doctor
   • Hospital
   • Partner
   • Child
   • Other relative
   • Friend
   • Paid support person/Carer/staff in residential home
   • Other

IF NOT DOCTOR
SHOWCARD 54.
Q175. Do you have a doctor who you can see if you get ill?
   IF YES

Q176. Do you get on well with your doctor?
   • Yes
   • No
   • DK - See lots of different doctors

Q177. Have you been to the doctor in the last year?
Q178. Have you had any toothache or pain in your teeth in the last 6 months? (amended HSE)
SHOWCARD 55. (and for next two questions)
Q179. Have you been to the dentist in the last year?
Q180. *Do you just go to the dentist when your teeth hurt, or do you go for a check up as well? (amended HSE)*

Q181. Have you had your eye sight tested this year?

Q182. Have you had your hearing tested this year?

WOMEN ONLY

Q183. Have you ever had a cervical smear test?

Q184. Have you ever had your breasts checked for lumps by a doctor or nurse?

LEVEL 3

Q185. *Can I just check - Is XXX registered with a GP*

Q186. *And are they registered with a dentist*

IF SUPPORT PERSON PRESENT

Q187. *INTERVIEWER TO CODE - Who answered majority of level 1 questions ON MEDICAL TREATMENT*

- Individual alone
- Support worker alone
- Individual and support worker together

Q188. *INTERVIEWER TO CODE - Who answered majority of level 2 questions ON MEDICAL TREATMENT*

- Individual alone
- Support worker alone
- Individual and support worker together

LEISURE ACTIVITIES

Q189. Now thinking about what you do in your free time. Do you choose what you do in the daytime or do other people tell you what to do? (amended CIP)

Q190. And do you choose what you do in the evenings?

Q191. Do you ever go to a day centre?

NOTE – find out the name of the day centre to substitute in the next few questions

Q192. How many days a week do you go to XX?

Q193. Do you like going to XX?

Q194. Are the staff at XX nice and polite to you? (CIP)
SHOWCARD 59. a, b & c (keep showcard ref on screen throughout)

Q195. I want you to think know about other things you do in your free time. In the last month have you gone …

- Shopping?
- To the pub or a club?
- For a meal in a restaurant or pub or cafe?
- To the library? (includes mobile library?)
- To play sport or go swimming
- To visit friends or family?
- To a hairdresser?
- To watch sport? (not on TV)
- To the cinema, or to plays or concerts Amended PSE items

FOR EACH THEY HAVE DONE IN LAST MONTH ASK

Q196. And do you like going

- Shopping?
- *To the pub or a club?
- *For a meal in a restaurant or pub or cafe?
- To the library? (includes mobile library?)
- To play sport or go swimming
- *To visit friends or family?
- To a hairdresser?
- To watch sport? (not on TV?)
- To the cinema, or to plays or concerts

FOR EACH THEY DON’T DO ASK

Q197. Would you like to go … more often

- Shopping?
- *To the pub or a club?
- *For a meal in a restaurant or pub or cafe?
- To the library? (includes mobile library?)
- To play sport or go swimming
- *To visit friends or family?
- To a hairdresser?
- To watch sport? (not on TV?)
- To the cinema, or to plays or concerts

NB – ASK ALL QUESTIONS ABOUT ONE ITEM AND MOVE ON TO NEXT.

Q198. IF NOT SAID HAVE MEAL IN RESTAURANT AT LEAST ONCE A MONTH - Do you always eat at home or do you sometimes go out to eat? (CIP)

SHOWCARD 60.

Q199. Have you been on holiday in the last year?

Q200. ASK ALL Do you sometimes go out on day trips?

Q201. What, if anything, would you like to be different about what you do in the daytime?

Q202. What, if anything, would you like to be different about what you do in the evening?
Q203. Would you like to have more say in what you do in your everyday life?

Q204. What do you enjoy doing most of all in your free time?

Q205. Do you get to do this often enough? Would you like to do this more?
- Yes – do it enough
- No – would like to do it more

Q206. If you wanted to know about things to do in your free time, who would you ask?
- Parent
- Partner
- Child
- Other relative
- Friend
- Paid support person/Carer/staff in residential home
- At the library
- At a college/place would get education/training
- Social Worker/Key worker
- Other

IF SUPPORT PERSON PRESENT
Q207. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON LEISURE ACTIVITIES
- Individual alone
- Support worker alone
- Individual and support worker together

Q208. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON LEISURE ACTIVITIES
- Individual alone
- Support worker alone
- Individual and support worker together

SOCIAL RELATIONSHIPS/NETWORK/SUPPORT

SHOWCARD 61.
I am now going to ask some questions about your family and friends

Q209. Do you ever see anyone in your family (apart from the people you live with)?

Q210. IF YES – Do you see them every day or nearly every day?

Q211. IF NO – Do you see them every week or nearly every week?

Q212. IF NO – Do you see them at least a few times a year?

Q213. Do you have friends you like to talk to or do things with? (outside of your family?) (CIP)

NOTE – get them to tell you who their friends are to help with the next questions
Q214. IF YES Do any of these friends have a learning difficulty?

Q215. IF YES Do you see any of your friends with learning difficulties every day, or nearly every day?

Q216. IF NO – Do you see them every week or nearly every week?

Q217. IF NO – Do you see them at least a few times a year?

Q218. (IF YES AT Q184 otherwise assume friends do not have learning difficulty) Do you have any friends who do not have a learning difficulty outside of your family?

Q219. IF YES – Are these/your friends/ all paid support workers? (wording depends if some of friends have learning difficulties or not)

Q220. IF NO – Can you think about your friends who don’t have learning difficulties and who are NOT support workers? Do you see any of them every day or nearly every day?

Q221. IF NO – Do you see them every week or nearly every week?

Q222. IF NO – Do you see them at least a few times a year?

(Above questions amended PSE)

Q223. Can you see your friends and family as often as you want to see them or would you like to see them more often?

SHOWCARD 62. a&b

Q224. IF NO – what stops you seeing them more often? (amended PSE)

- Not enough money
- Not enough time
- Travel problems - can’t get there/too far
- Too ill/disabled – can’t get out
- Fear of going out (e.g. bullying)
- Need someone to help me – not always anyone to help
- Other

IF SUPPORT PERSON PRESENT

Q225. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON SOCIAL RELATIONSHIPS

- Individual alone
- Support worker alone
- Individual and support worker together

ACCESS AND INVOLVEMENT ISSUES (INC TRANSPORT)

SHOWCARD 63.
I want you to think now about when you want to get somewhere

Q226. When you want to go somewhere, do you usually need someone to go with you?

- Yes
- No
- Depends where I am going/how far
Q227. IF NEED HELP – Is there usually someone around who can help you when you want to go somewhere or do you usually have to wait until some other time? IF DON'T NEED HELP/DEPENDS - When you want to go somewhere can you usually get there? (CIP)

Q228. How do you usually get to places?

READ OUT IF NECESSARY

- Walk / (in wheelchair)
- Taken by family / friends in car
- Taken by special bus/car with other people with learning difficulties
- Taxi
- bus / tram (Public transport)
- Train
- Tube
- Bike

SHOWCARD 64.

Q229. Do you ever have problems using public transport?

- Yes
- No
- NEVER USE

IF NEVER USE PUBLIC TRANSPORT SKIP TO Q215

Q230. Do you feel safe using public transport?

SHOWCARD 65.

Q231. So, how easy is it for you to use public transport?

- Very easy
- Fairly easy
- Not easy

SHOWCARD 66.

Q232. How helpful do you usually find the staff on public transport?

- Very helpful
- Fairly helpful
- Not helpful
- ADD CODE – Always with someone so don’t deal with staff

SHOWCARD 67.

Q233. Have you had training in using public transport?

IF NO

Q234. Would you like some training?

SHOWCARD 68.

Q235. Have people been rude or nasty to you because of your learning difficulty in the last year?
Q236. *Who was rude or nasty to you?*

- Paid support worker/carer/staff at residential home
- Someone they live with (not support worker)
- Someone at day centre (not support worker)
- Someone they work with
- A stranger/someone they did not know
- Other (specify)

SHOWCARD 69.

Q237. Have you been the victim of a crime in the last year? (compare BCS)

IF YES

Q238. How many times?

Q239. *What happened to you last time?* NOTE: THIS IS ABOUT DETAILS OF THE CRIME NOT WHAT HAPPENED NEXT

Q240. Did you tell the police about it?

IF YES

Q241. *What did they do?*

SHOWCARD 70.

Q242. When you want to know something, is it easy to find out in a way you can understand? IF NECESSARY – can you usually find out what you want to know?

SHOWCARD 71.

Q243. Did you vote in the last general election?

Q244. *Have you heard of the Government White Paper “Valuing People” before today?* (use information sheet to remind what it is if necessary)

Q245. *Have you heard of the National Forum for people with learning difficulties?*

Q246. *Do you think this will let people with learning difficulties have their say?*

SHOWCARD 72.

Q247. Do you have a person other than your family who helps you to speak up? (amended CIP) (=INDEPENDENT ADVOCATE)

IF YES

Q248. Are they paid to help you speak up or do they do it in their own time?

SHOWCARD 73.

Q249. *Do you know about any groups in your area which can help you speak up?* (=Self-advocacy groups)

Q250. *Have you ever taken part in a meeting where you put forward your views and help say what sort of services you need?* (amended CIP)

IF YES

Q251. *Do you go to these sorts of meetings often?*

Q252. *Do these let people with learning difficulties speak up?*
IF SUPPORT PERSON PRESENT

Q253. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON ACCESS AND INVOLVEMENT

- Individual alone
- Support worker alone
- Individual and support worker together

Q254. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON ACCESS AND INVOLVEMENT

- Individual alone
- Support worker alone
- Individual and support worker together

SUPPORT SERVICES AND INITIATIVES

Thinking about all the things you need support or help with …

SHOWCARD 74.

Q255. How happy are you with the support you get?

- Very happy
- Quite happy
- Not happy

Q256. Who arranges this support for you? (if necessary – who would you go to if you needed support or help with anything)

- Family member
- Friend (not paid)
- Paid support person/ staff at residential home
- Social Worker/ Care Manager
- Key Worker/ Care worker
- Other (specify)

UNLESS SAID FRIEND OR FAMILY MEMBER

SHOWCARD 75.

Q257. Have you ever wanted to complain about the support you get?

- Yes
- No

Q258. Have you heard of your local Learning Disability Partnership Board? They are there to make sure services are available for people like you.

Q259. Have you or your family been involved in your local Partnership Board?

Q260. Have you heard of the National Learning Disability Information Centre or helpline? (They can provide information for people with learning difficulties)

IF NECESSARY - helpline number is 0808 808 1111 – minicom 0808 808 8181
Q261. Have you ever contacted them or called their helpline?

IF SUPPORT PERSON PRESENT

Q262. INTERVIEWER TO CODE - Who answered majority of level 1 questions ON SUPPORT SERVICES AND INITIATIVES

- Individual alone
- Support worker alone
- Individual and support worker together

Q263. INTERVIEWER TO CODE - Who answered majority of level 2 questions ON SUPPORT SERVICES AND INITIATIVES

- Individual alone
- Support worker alone
- Individual and support worker together

KEY TO SOURCE OF QUESTIONS

Census – 2001 Census
CIP – US Core Indicator Project – survey of people with developmental disabilities
HSE - Health Survey for England
GHS - General Household Survey
PSE – Poverty and Social Exclusion Survey
SP - Supporting People User Survey – questions developed for ODPM survey – wording adapted