Interview schedule
-
for interviewing main family carers of people with learning disabilities

Who are you to the person you care for?
- parent
- partner
- sibling
- other, please state……

PART I About person you care for and about you

a) About person you care for

1. How old is …?
2. Code: sex
3. Where does … live? (name of the village/town/city)
4. What type of accommodation does … live in? Is it:
   - House
   - Flat
   - Mobile home
   - Room in residential home
   - Hospital
5. About how long has … lived there?
   - Less than 5 years
   - Longer than 5 years
   - Longer than 10 years
   - All her/his life
6. What is … ethnicity? Is s/he… **[card 1]**
7. How would you describe … nationality?
8. What is … country of birth?
9. [If not born in the UK] When did … arrive in the UK?
10. How does this person communicate?
11. Is English … main language?
    IF YES – q.14
    IF NOT – q.12
12. What is … main language/dialect?
13. How well can … speak English?
14. What is … religion?

b) About you

1. Code: sex
2. What is your ethnicity? Are you … **[card 2]**
3. How would you describe your nationality?
4. What is your country of birth?
5. [If not born in the UK] When did you arrive in the UK?
6. Is English your first language?
   IF YES – q.9
   IF NOT – q.7
7. What is your main language/dialect?
8. How well can you speak English?
9. What is your religion?

PART II. Understanding a learning disability condition and needs assessment

1. Can you tell me a little bit about …?
2. Do s/he has a difficulty or difficulties that s/he have had for a long time?
IF YES What is it?
[prompt:]
    - Learning disability
    - Learning difficulty
    - Physical disability
    - Difficulty seeing
    - Difficulty hearing
    - Difficulty speaking
    - Mental health problem
    - Epilepsy
    - Autism
    - Other
3. How did you find out? [prompt:] Was it a doctor, a nurse, a teacher, a social worker?
4. When was it? [how long after coming to the UK]
5. How did you feel about the way you found out?
6. Is s/he able to cope independently or does s/he need someone's help?
7. I want you to tell me for each thing whether s/he needs help with:
    - Getting dressed in the morning
    - Having a shower or a bath
    - Preparing something to eat
    - Eating and drinking
    - Washing clothes
    - Spending money
    - Going out (for example for a walk)
    - Ordering something to eat or drink
    - Going to a bank or Post Office
    - Making an appointment (for example to see a doctor)
    - Filling in a form (for example when applying for a job)

PART III. Support received

Language

8. Does … need help when communicating in English?
    IF YES – go to q.9
    IF NO – go to q.11
9. Who is helping …?
10. Is this help satisfactory?
11. Do you need help when communicating in English?
    IF YES – go to q.12
    IF NO – go to q.14
12. Who is helping you?
13. Are you satisfied with this help?

Access to support

In England, people with difficulties similar to those that … has, may receive support to cope better in their everyday lives. I would like us to talk about support that s/he needs.

14. Has any support been offered?
    IF YES – go to q. 15
    IF NOT – go to q. 20
15. Have you accepted this support?
    IF YES – go to q. 16
    IF NOT – go to q. 19
16. What support has been offered?
17. Is … life better or worse since then?
18. In what ways is it better/worse?
    GO TO q.21
19. Why didn't you accept support offered?
    GO TO q.21
20. How do you cope without support? [prompt:]
    Is anybody else helping you?
    Would you like help other than of your family?

A support worker/a care manager

21. Has … ever had a meeting to plan care?
22. Does … have or had a support worker or a care manager?
    IF YES – q.23
    IF NOT – q. 29
23. For how long has … had the social worker/care manager? / For how long …had the social worker/care manager? [prompt]
    •Only a few weeks
    •A few months
    •Up to a year
    •More than a year
24. How often does s/he see the social worker/care manager? / How often did s/he see the social worker/care manager? [prompt]
    • every week
    • a few times a month
    • once a month
    • every couple of months
25. Does … and you understand what the social worker/care manager says or do you need help with understanding what is said to you? / Does … and you understood what the social worker/care manager was saying or did you need help with understanding what was said to you?
26. Does the social worker/care manager come to visit when … or you ask? / Did the social worker/care manager come to visit when … or you asked?
27. Does the social worker/care manager listen to what … or you have to say? / Did the social worker/care manager listen to what … or you had to say?
28. In what ways do you feel that the social worker/care manager listens/doesn't listen to you? In what ways did you feel that the social worker/care manager listened/didn't listen to you?
    GO TO q.30
29. Why … does not have a support worker/a care manager anymore?

Where … live

30. Where and with whom does … live?
31. Is it a good place to live? Why?
32. Has there ever been any help needed to find a place to live for …?
    IF YES – q. 33
    IF NOT – q.35

33. Who found the place for … to live? [prompt]
    - 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)
34. Was this help satisfactory?

Money

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

35. Does … receive any benefits?
    IF YES – q.36
    IF NOT – q.38
36. And what benefits does s/he you receive? [prompt]
    - Disability Living Allowance
    - Severe Disability Allowance
    - Income Support
    - Incapacity Benefit
    - Housing Benefit
    - Other
37. Does s/he have a Personal Budget?
38. Do you receive a benefit for carers? [prompt]
    - Earnings replacement benefit (for example carer's allowance)
    - Income support
    - Carers Personal Budget

Job

I am now going to ask you some questions about … employment.

39. Does … have a job at the moment?
    IF YES – q.43
    IF NOT – q. 40
40. Would s/he like to have a job?
    IF YES – q.41
    IF NOT – q.42
41. Why doesn't s/he have a job?
    GO TO - q.46
42. Why doesn't s/he want a job?
    GO TO - q.46
43. Is the job good for …?
44. Did s/he choose the job?
45. Is s/he paid to do this job?

I am now going to ask you some questions about looking for a job

46. Has s/he been offered any training to help to take up a job?
47. Did s/he (does s/he) get any help when looking for a job?
    IF YES – q.48
    IF NOT – q.50
48. Who from? [prompt]
    - Parent
    - Partner
    - Other relative

- Friend
- Paid support person / carer / staff at residential home
- Social Services
- Job Centre
- Other (STATE)

49. Was this help satisfactory?

Education and training

I would like us to talk now about … education of

School

50. Did … go to a school in England?
    IF YES – q.51
    IF NOT – q.54
51. Did … go to an ordinary school or a special school?
    IF *ORDINARY SCHOOL* – q.52
    IF SPECIAL SCHOOL – q.53
52. Did … go to a special needs unit at your school, or was s/he in the main school?
    GO TO q. 53
53. How was school for her/him?
    GO TO q. 55
54. Why didn't … go to a school in England?

Training

55. Is … doing any courses or training at the moment?
    IF YES – q.56
    IF NOT – q.57
56. Is this at college, at work, at a day centre or somewhere else?
    GO TO – q.58
57. Would it be good for … to do a course or training?

Health

I am now going to ask you some questions about … health

58. How is …. health?
59. Is … registered with a doctor?
    IF YES – q.60
    IF NOT – q.64
60. Does … get on well with the doctor?
61. Does … have health checks? A health check, done annually, can pick up on health problems so people can get the right treatment.
62. Does s/he have a health action plan?
63. Why isn't … registered with a doctor?
64. Has s/he received health advice from a dietitian?
65. Is s/he registered with a dentist?
    IF YES – q.66
    IF NOT – q.67
66. Does s/he go to the dentist for checkups?
    GO TO Q.68
67. Why isn't … registered with a dentist?
68. Does s/he have her/his eye sight tested regularly?
    IF YES – q.70
    IF NOT – q.69

69. Why not?
70. Does … have her/his hearing tested regularly?
    IF YES – q.72
    IF NOT – q.71
71. Why not?
72. Does … ever feel sad or worried?

WOMEN ONLY
73. Has she had a cervical smear test?
74. Has she had her breasts checked for lumps by a doctor or nurse?

Day opportunities

Now thinking about what s/he does during daytime.
75. Usually, what does s/he do and where does s/he go on each day of the week? **[a weekly day schedule-please fill in]**

Ask accordingly for each activity:
76. Does … like going there?
77. Are the staff nice and polite there?

78. What else, if anything, would be good for … to do?

Travelling

I want you to think now about when … want to get somewhere
79. When … wants to go somewhere, does s/he usually need someone to go with her/him?
    IF YES – q.80
    IF NOT – q.81
80. Is there usually someone around who can help her/him when you want to go somewhere or does s/he usually have to wait until some other time?
    GO TO q.82
81. When … want to go somewhere can s/he usually get there?
82. If … uses public transport, does s/he ever get problems?
83. Is it safe for … to use public transport?
    IF YES – q.85
    IF NOT – q.84
84. In what ways it is unsafe?
85. So, how easy is it for … to use public transport?
86. How helpful is the staff on public transport?
87. Has … had training in using public transport?
    IF YES – q.89
    IF NOT – q.88
88. Would it be good for … to have training?

Caring for children

89. Does s/he have children?
    IF YES – q.90
    IF NOT – q.97
90. How many?
91. Does s/he look after the children/ child?
    IF YES – q.92
    IF NOT – q.96

92. Does anyone help her/him to look after them/it?
    IF YES – q.93
    IF NOT – q.95
93. Who is it?
94. Is this help suitable?
95. Is there more help needed to look after the child / children?
    GO TO Q. 97
96. Why isn't s/he looking after her/his children?

Interaction with other people

97. How is … life in the community?
98. Have people been rude or nasty to … because of learning disability?
    IF YES – q.99
    IF NOT – q.100
99. Who was rude or nasty to …? [prompt]
    - 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
    - Someone at school
    - A stranger/someone they did not know
    - Other, please specify

Having your say

100. Is there a person or a group who helps you to speak up about the services need for … and for you as a carer? This is called self-advocacy.

PART IV Improving access to the services and its appropriateness

101. Thinking about the needs … has, are all of them satisfied?
    IF YES – q.103
    IF NO – q. 102
102. What are the needs and why are they not satisfied?
103. What is the best thing about support that … receives?
104. Is there any bad thing about this support?
105. Is there anything that would make this support get better?

PART V ASSESSING CARER'S NEEDS

1. What does your life as a carer look like?
2. In what way has caring for … affected your life?
    2a. your employment
    2b. your health
    2c. your relationships with others
    2d. your wellbeing (e.g. time for yourself)
3. Do you get enough support in caring for…
    IF NOT What other support would help you?

Closing questions:

Is there anything else that you would you like to add to what you said?
Is there anything else that you would like to talk to me about that would help us to understand the situation of people with needs similar to those of … and their carers?