

Adult social care

In this section we ask adults with Down syndrome to complete as much of the questionnaire as possible.

We understand this may be difficult, so it may be helpful to have assistance from a parent/carer.

Anything you write will be anonymous (your name will not be shared).

* 1. How do you describe yourself/in what capacity are you completing this survey?

- | | |
|---|--|
| <input type="checkbox"/> I have Down syndrome | <input type="checkbox"/> I am a family relative of someone with Down syndrome |
| <input type="checkbox"/> I am a parent/carer of someone with Down syndrome and am answering with my views | <input type="checkbox"/> I am a friend to someone/some people with Down syndrome |
| <input type="checkbox"/> I am completing with someone with Down syndrome and supporting them to share their views | |
| <input type="checkbox"/> Other (please specify) | |

2. What is your gender?

- Female
- Male
- Prefer not to say
- Other (specify)

* 3. What is your age?

- Under 18
- 18-25
- 25-40
- 40-50
- 50-60
- 60+
- Prefer not to say

4. What ethnicity are you?

- Asian or Asian British
- Black, Black British, Caribbean or African
- Mixed or multiple ethnic groups
- White
- Other ethnic group
- Prefer not to answer
- Other (please specify)

* 5. Where do you live?

- | | |
|--|--|
| <input type="radio"/> Scotland | <input type="radio"/> West Midlands |
| <input type="radio"/> Northern Ireland | <input type="radio"/> East England |
| <input type="radio"/> Wales | <input type="radio"/> London |
| <input type="radio"/> North East England | <input type="radio"/> South East England |
| <input type="radio"/> North West England | <input type="radio"/> South West England |
| <input type="radio"/> Yorkshire and the Humber | <input type="radio"/> Channel Islands |
| <input type="radio"/> East Midlands | |

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* 6. How old is the family member/friend with Down syndrome?

- Under 18
- 19-25
- 25-40
- 40-50
- 50-60
- 60+

* 7. Where does your family member/friend with Down syndrome live?

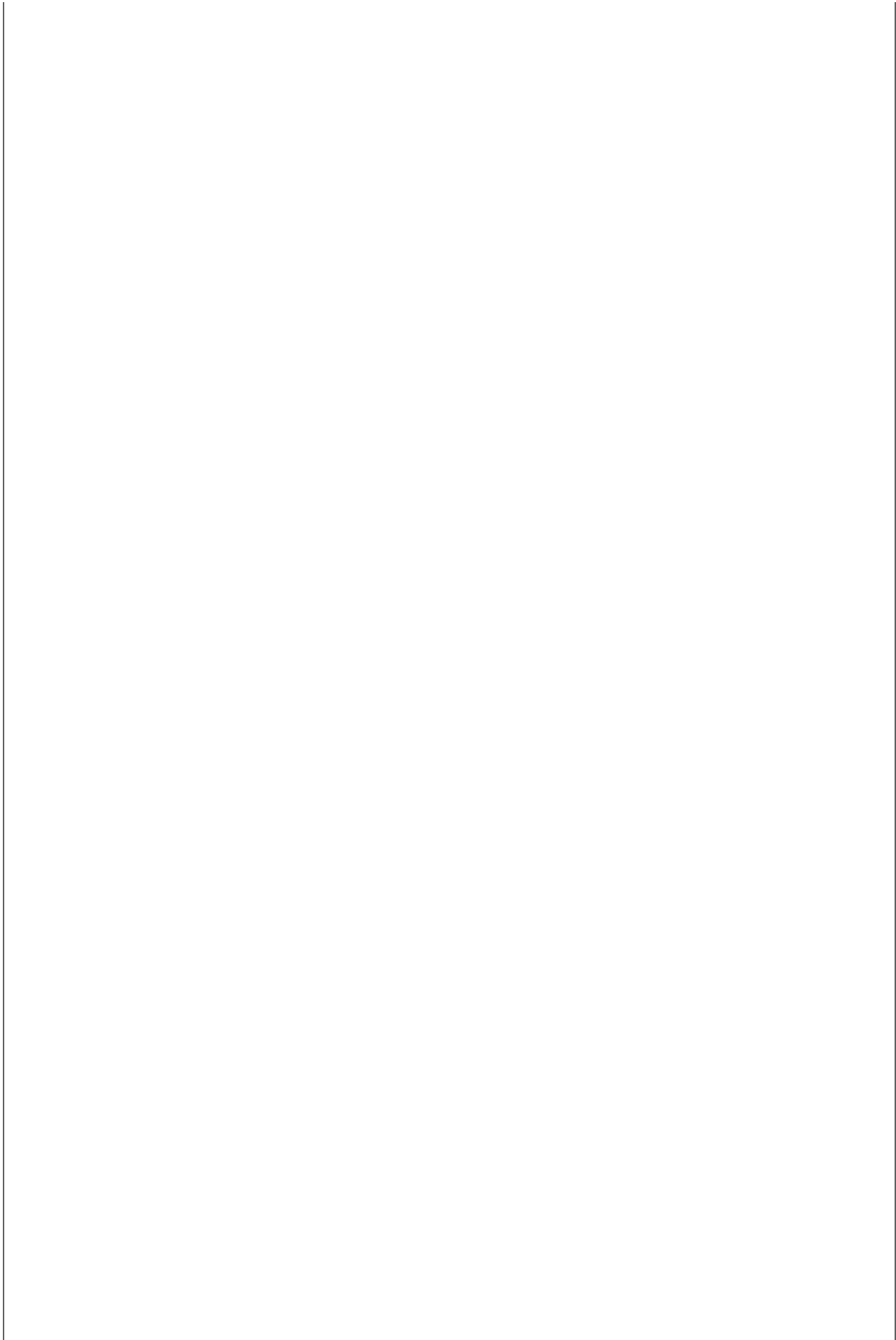
- | | |
|--|--|
| <input type="radio"/> Scotland | <input type="radio"/> West Midlands |
| <input type="radio"/> Northern Ireland | <input type="radio"/> East England |
| <input type="radio"/> Wales | <input type="radio"/> London |
| <input type="radio"/> North East England | <input type="radio"/> South East England |
| <input type="radio"/> North West England | <input type="radio"/> South West England |
| <input type="radio"/> Yorkshire and the Humber | <input type="radio"/> Channel Islands |
| <input type="radio"/> East Midlands | |

8. What gender is your family member/friend with Down syndrome?

- Female
- Male
- Prefer not to say
- Other (please specify)

9. What ethnicity is your family member/friend with Down syndrome?

- Asian or Asian British
- Black, Black British, Caribbean or African
- Mixed or multiple ethnic groups
- White
- Other ethnic group
- Prefer not to answer
- Other (please specify)



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10. Do you have a social worker to support you?

A social worker is generally someone who works for your local authority/council and they provide you with information about social care support you can receive.

- Yes
- No
- Not sure

11. If yes, does the social worker help you?

- Yes
- No

12. If your social worker has helped you, please share some information about how they help you.

13. If you do not have social care support, why do you not have social care support?

Social care support is when you are given money that can be used to pay for a PA or social care worker, or to go to clubs, to pay for someone to help in your home etc.

- I have not been offered it
- I didn't know I was able to have social care support
- I don't feel the need for it
- I have asked but not been given any support
- I don't want any support
- Not sure
- Other (please specify)

14. Do you find it easy or difficult to understand what services you can have from the social care system?

15. Are there any people or organisations you turn to when unsure about how to access social care support? If so, please share details e.g. family member, charity, local authority support, medical practitioner etc.

16. Do any of the following worry you at all?

	Yes I am worried	No I am not worried	I am not sure/this is not applicable
Housing (where you live)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment (a job)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Safety/security (being safe)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationships (friendships, partnerships)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health & wellbeing (how well you feel mentally and physically)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finances (money)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. Do you think your social worker understands what you need?

- Yes
- No
- Not sure

18. Thinking about your physical health, how well do you think you are being helped/supported?

Physical health includes making sure you eat well, and do exercise, keeping yourself fit and healthy.

I am helped/supported very well	I am helped/supported quite well	I am not helped/supported well	I am not sure
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. Thinking about your mental health/emotional wellbeing, how well do you think you are being helped/supported?

Mental health/emotional wellbeing includes how you feel about things - whether you worry or are anxious, or are depressed, feel happy or sad.

I am helped/supported very well	I am helped/supported quite well	I am not helped/supported well	I am not sure
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. What is your current living situation, please tick one of the following:

- I live on my own
- I live with my brother or sister or another family member
- I live with a friend or partner
- I live with others in a shared home
- I live with my parent(s)
- Other (please specify)

21. Please share what support you receive from social care.

This may be at home helping you to plan your week, to do the washing or cooking. It may also be to help you to go to different places, perhaps to go shopping, to a social group or to work.

22. How many hours support do you receive each week from social care?

Please help us to understand what the time is for, eg 12 hours a week, to support me to attend drama club and volunteering at a cafe, and 6 hours a week at home to support me with my money and food planning.

23. Do you think that you have enough support to live the life you want to live? Or do you think you need more support so you can do more?

24. Does your family access respite care?

- Yes
- No
- Don't know

25. Thinking about the care you receive - which of the following Care Act outcomes are you supported with:

- | | |
|---|--|
| <input type="checkbox"/> Managing and maintaining nutrition | <input type="checkbox"/> Maintaining a habitable home environment |
| <input type="checkbox"/> Maintaining personal hygiene | <input type="checkbox"/> Developing and maintaining family or other personal relationship |
| <input type="checkbox"/> Managing toilet needs | <input type="checkbox"/> Accessing and engaging in work, training, education or volunteering |
| <input type="checkbox"/> Being appropriately clothed | <input type="checkbox"/> Making use of necessary facilities or services in the local community, including public transport and recreational facilities or services |
| <input type="checkbox"/> Being able to make use of your home safely | <input type="checkbox"/> Carrying out any caring responsibilities you have for a child |

26. Is there anything else you would like to share with us about your social care?

27. If you are happy for us to contact you about this survey, the Down Syndrome Act or guidance, please provide your details.

You do not have to provide your details, it is your choice.

Name

Email Address

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