

Social care for children and young people under 18 years of age

This survey is intended to be completed by those who are family members/friends of someone with Down syndrome under the age of 18 years. For adults with Down syndrome, there is a separate survey.

Data will all be presented anonymously, unless express permission is obtained.

* 1. In what capacity are you completing this survey?

- I am a parent/carer of someone with Down syndrome and am answering with my views
- I am a family relative, other than parent, of someone with Down syndrome
- I am a friend to someone/some people with Down syndrome
- Other (please specify)

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

- Under 1
- 1-4
- 5-10
- 11-18
- 19-25
- 25-40
- 40-50
- 50-60
- 60+

* 3. 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 | |

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

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

5. What ethnicity is your family member/friend with Down syndrome, or if completing as a professional the ethnic groups of the people with Down syndrome you generally work with each associate with?

- 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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6. Does your child/young person have an allocated social worker?

A social worker is generally employed by the local authority and is your main point of contact around accessing social care.

- Yes Requested but declined
- Not requested Had previously but no longer
- Requested and awaiting
- Other (please specify)

7. If yes, have you found the social worker has helped your child/young person?

- Yes
- No
- Other (please specify)

8. If the social worker has helped, please provide some examples about how they have helped?

9. How long was it from requesting a social worker, that a social worker was assigned? (months)

10. From what age has your child/young person had a social worker?

- Under 2 years old Between 11-16 years old
- Between 2-4 years old Over 17 years old
- Between 5-10 years old Never

11. If any, what social care support does your child/young person currently access?

Please give details/quantify the support, e.g.

4 hours Direct payments per week in holidays.

2 hours Direct payments per week during term.

Access to 2 hourly take a break club once a week.

An overnight stay with volunteer family once a month.

Overnight respite stay once a month at local authority provision etc.

12. If you do not have social care support, why not? Please tick all that apply.

- I have not been offered it
- I don't feel the need for it
- I don't think we are eligible for social care support
- I don't want social care involvement
- Other (please specify)

13. How have you found understanding the social care system?

14. How knowledgeable do you feel about what your child/young person is entitled to with regard to social care now?

1 being not knowledgeable, 5 being extremely knowledgeable

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. Which individual(s) or organisation(s), e.g. family, charity, local authority support, medical practitioner, etc do you turn to when unsure about accessing social care services to support your child/young person?

16. How well do you feel that the social care needs of your child/young person are being met by your local authority services now?

(1 not being met well, 5 being met very well)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. How confident do you feel that the social care needs of your child/young person will be met by your local authority services when they are an adult?

(1 is not confident, 5 is very confident)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. Please comment on what influenced your scores?

19. Please rate the aspects of adult living that give you the most concern for your child/young person, with 1 being the least (not concerned) through to 5 the highest (extremely concerned).

	1	2	3	4	5
Housing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Safety/security	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health and wellbeing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

20. What do you consider to be 'best practice' of social care for adults with Down syndrome?

How would you like your child/young person to be supported by social care services when they reach adulthood?

21. When speaking with your local authority about social care, to what extent do you feel they have tried to understand your child/young person's social care needs?

(1 is not at all, 5 is they really understood)

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

22. Please provide examples of how local authorities have tried/not tried to understand your child/young person's social care needs.

23. As a parent/carer, do you think that your opinion is important to the social care professionals there to support your child/young person?

- Yes
- No
- Not sure

24. Have you as a parent/carer had a Carer's Assessment?

- Never
- Within the past 12 months
- Between 1-2 years ago
- Between 2-5 years ago
- More than 5 years ago

25. Anything else you would like to share about social care either from your own experiences and/or hopes/concerns for the future?

26. If you are happy for us to contact you with regard to this survey, the Down Syndrome Act or Guidance, please provide details.

Name

Email Address