

Parental experience around transitioning to/starting adult social care

In this survey we are seeking the experiences of parents of folk with Down syndrome aged 16+ around transitioning to/entering adult social care.

1. Are you parent/carer to someone with Down syndrome who is aged 16 years and over, and based in the UK?

Yes

No

Parental experience around transitioning to/starting adult social care

2. What is the gender of your family member with Down syndrome?

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

3. What ethnicity is your family member 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)

* 4. Where does your family member with Down syndrome live?

- Scotland
- Northern Ireland
- Wales
- North East England
- North West England
- Yorkshire and the Humber
- East Midlands
- West Midlands
- East England
- London
- South East England
- South West England
- Channel Islands

* 5. How old is your family member with Down syndrome?

- 16 years
- 17 years
- 18 years
- 19-25
- 25-40
- 40-50
- 50-60
- 60+

Parental experience around transitioning to/starting adult social care

6. Does your family member have an allocated social worker?

A social worker is generally employed by your local authority and is your main point of contact to access social care.

- Yes Requested but declined
 No Previously but not any more
 Requested but not yet allocated Not sure
 Other (please specify)

7. If yes, since what age have they had an allocated social worker?

8. If your family member does not currently access any social care support, why do you not have social care support? (please tick all that apply).

Social care support is support funded via social services, this may include Direct Payments, or a place at a funded play scheme, or overnight care at a residential care setting.

- My family member has not been offered it
 We don't feel the need for it
 We didn't know my family member was able to have social care support
 We've not wanted to have social care support
 Other (please specify)

9. How easy or difficult do you find it to understand what services/support your family member can have from the social care system?

10. 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.

11. Do any of the following worry you for your family member in the future?

	Yes I am worried	No I am not worried	I am not sure/this is not applicable
Housing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Safety/security	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health & wellbeing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. What is your family member's living status at present?

For example, at home full time, in their own home, with a friend/partner in their own home, in residential care, at residential college during term time etc....

13. Do you as a family access respite care?

- Yes
- No
- Don't know

Parental experience around transitioning to/starting adult social care

Transitioning to adulthood

14. Transitioning to adult social care - do/did your family member have a social worker from the transitions team?

- Yes Requested but declined
 Not requested Not sure
 Requested but not yet accessed
 Other (please specify)

15. If you have/have had a social worker specifically around transitioning, please share

Who initiated this - did you request or did your local authority contact you?

How long did it take to be allocated a transitions social worker?

16. Has your family member been assessed for eligibility for an adult social care plan?

- Yes
 No
 Not sure
 Other (please specify)

17. At what age was/is your family member when an assessment was conducted/due to be conducted?

18. Has an adult social care plan been issued for your family member?

- Yes
- No
- In the process
- Not sure
- Other (please specify)

19. At what age was your family member when their adult social care plan was issued?

20. Are you satisfied with the adult social care plan? Please share your experience around the process.

21. Please share the hours/budget your family member is given within their adult social care plan.

22. How have you found the experience of transitioning to/starting in adult social care?

23. Any other comments you wish to share around adult social care

24. If you are happy for us to contact you with regard to this survey, the Down Syndrome Act and guidance, please provide details.

Name

Email Address