

DOWN SYNDROME ACT CALL FOR EVIDENCE

Guidance for Responding

This document aims to provide guidance to people who are affected by genetic conditions and organisations that support them who are interested in responding to the [Government's call for evidence on the Down Syndrome Act](#). The Government made a commitment as the Down Syndrome bill was progressing through Parliament to consider whether the support needs of people with Down's syndrome and people with a different or other genetic condition are similar.

Genetic Alliance UK believes there is a very large overlap between the needs of people with many genetic and rare conditions and those living with Down's syndrome. We are therefore very keen for the call for evidence to gather evidence to show this.

The Act requires the Government to develop guidance for relevant authorities (for example, NHS hospitals or local councils) on the appropriate steps those authorities may need to take to meet the needs of people with Down's syndrome - and potentially other genetic conditions - when carrying out some of their most important functions.

The Act will be implemented through guidance, based on the feedback received during this call for evidence. **If you or your community might be affected by this Act, it is important to engage now before the guidance is developed.**

This consultation closes at 11:45pm on 8 November 2022.

The link to respond is here:

gov.uk/government/consultations/down-syndrome-act-2022-guidance-call-for-evidence

If you have any comments or questions, please contact: sophie.peet@geneticalliance.org.uk

This document contains:

- 1 - [Tips to respond](#)
- 2 - [Questions for a person with other genetic condition or learning disability](#)
- 3 - [Guidance for parent/carers/family members](#)
- 4 - [Questions for parent/family/carers](#)

1 Tips to respond

The guidance will cover a wide range of services including NHS, social care, education, youth offending and housing **but you don't have to answer all of the questions**, just answer what you can.

Down's syndrome is a complex condition that causes multisystemic symptoms including:

- Heart issues
- Infections and immunisations
- Cancer risk
- Epilepsy and seizures
- Gastrointestinal issues
- Diabetes
- Sleep disturbances
- Ears, nose and throat issues
- Bone and muscles
- Emotions and moods
- Ageing and dementia
- Autism
- Behavioural issues
- Speech and language issues

(This list is taken from the Down's Syndrome Association [webpage](#).)

If you or your community relies on services which are also provided to people with Down's syndrome, you may be affected by this Act.

You can read more about the Down Syndrome Act [here](#) and our full position statement [here](#).

2 Questions for a person with other genetic condition or learning disability

Survey Questions

What support do you need

- to keep healthy?
- from adult social care services?
- to live independently in your own home ?

What would help you get

- the health services you need?
- the adult social care services you need?

Are there examples of ... that you would like to share?

- when you have received good health care
- when you have received good adult social care support
- when you have received good housing support
- when you have received good support in school or college
- good social care for children and young people
- good support from youth offending teams

What would you like to see in the Down Syndrome Act guidance?

Is there anything else you would like to tell us about the guidance?

What you might want to consider

Does having a rare condition ever act as a barrier to services? I.e no set pathway

What services do you currently use or are trying to get access to?

Have you always been able to access care?

How long have you had to wait for care/services?

If you have had any good experiences of receiving care or support services that you would like to see replicated, please provide those details here.

Are there any support services you currently use that have not been mentioned in the survey?

Do you see any risks accessing support or care as a result of this guidance?

3 Guidance for parent/carers/family members

We received feedback from members of the community saying that they were struggling to complete the survey for the call for evidence on the Down Syndrome Act. After speaking to DHSC, they have confirmed that they are keen to hear the views of people from the rare and undiagnosed communities and so have provided guidance on how parent/carer/family members of someone with a genetic condition that is not Down's syndrome can respond.

At the beginning of the survey, parents and carers will still need to select the option 'carer or family member of someone with Down's syndrome'. See image below:

In what capacity are you responding to this survey? *

- An individual sharing my personal views and experiences
- An individual responding on behalf of someone else
- A carer or family member of someone with Down's syndrome
- An individual sharing my professional views
- On behalf of an organisation (including voluntary and charitable sector)
- An individual with other genetic condition or learning disability

The questions will specifically ask about Down's syndrome however there is now some instructional text as follows:

'For carers or family members of a person with 'other genetic conditions' please respond to the following questions based on your own experiences of the condition of the person you care for. Please indicate in your answers which condition you are referring to.'

4 Questions for parent/family/carers

N.B the questions in this section say Down's syndrome but parents/carers/family members of people with other genetic conditions should still answer these questions and provide the name of the condition they are referring to in their answers.

Questions

In your view, what are the specific ... of people with Down's syndrome?

- physical and mental health needs
- adult social care needs

Do you agree or disagree that the professionals listed understand how to support and communicate with people with Down's syndrome?

- GPs (doctors)
- nurses
- hospital doctors
- mental health professionals
- occupational therapists
- speech and language therapists
- opticians
- dentists
- health care assistants
- care workers
- community support workers
- residential support workers
- housing officers
- family support workers
- social workers
- social care assessors
- care coordinators
- registered managers
- personal assistants
- other

Do you think there are barriers in accessing ... for people with Down's syndrome?

- physical health services
- mental health services
- adult social care services
- housing support services

What you might want to consider

How does the condition impact physical and mental health?

What social care needs does the individual need?

How were your experiences dealing with each of these types of professionals?

Were they able to understand, support and communicate with you/the person you care for?

Have you always been able to access care/services?

How long have you had to wait for care/services?

Does having a rare condition ever act as a barrier to services? I.e no set pathway

Do you think it is easy to access information and advice about ... in your local area?

- healthcare services
- adult social care services
- housing support services

Do you have an example of a good experience of ... that worked to meet the needs of people with Down's syndrome you would like to share?

- physical or mental health services
- adult social care services
- housing support services
- education
- child and young people's social care services
- a youth offending team
- other public services

Could other people, such as those with other genetic conditions benefit from the same ...used to support people with Down's syndrome?

- health services
- adult social care services
- housing support services

Do you think there are differences in the ... of people with Down's syndrome and other genetic conditions?

- physical health needs
- mental health needs
- adult social care needs
- housing support needs

Do you know what support your local council could provide to support people with Down's syndrome to live independently in their own home?

What support would a person with Down's syndrome need to help them live independently in their own home?

If you have been searching for information about care or services, how easy was it to find?

If you found information, how easy was it to understand?

If you have had any good experiences of receiving care or support services that you would like to see replicated, please provide those details here.

Does the condition of the person you care for have overlapping symptoms with Down's syndrome?
Does the person you care for use the same services that someone with Down's syndrome may use?

Would the person you care for need additional or different provisions for better support relating to their physical health/mental health/social care/housing support needs compared to those with Down's syndrome?

If the person you care for lives independently, or intends to in the future, are you aware of what support your local council currently provides to support this?

If the person you care for lives independently, or intends to in the future, what support would they need to enable this?

Do you have any ideas of what support would help children and young people with Down's syndrome prepare for adulthood?

Other than health, social care, education, housing and youth offending, which other public services should, in your view, be considered for adding into the guidance?

Do you think there is more that could be done to support professionals to understand the needs of people with Down's syndrome?

Has the person you care for transitioned from childhood to adulthood? What challenges were there relating to care and services?

Are there any other public services you use while caring for someone?

What have your experiences of interacting with professionals while accessing healthcare and services been like? Were there things that could be done differently?