

Down Syndrome Act 2022 guidance: call for evidence – response from the Royal College of Speech and Language Therapists (RCSLT)

Professionals: questions

Questions about health services

Do you have views on physical and/or mental health services providing support to people with Down's syndrome you would like to share?

- Yes
- No

The themes from successive LeDeR reports are well known and documented nationally. The learning from this programme, therefore, informs our submission about the inequalities faced by people with Down's syndrome due to the fact that they have a learning disability:

- [2021 LeDeR report](#)
- [LeDeR annual reports](#)

RCSLT members report that there is often a lack of understanding of the abilities and needs of people with Down's syndrome. This can prevent them receiving the care they need.

It is important that the views of people with Down's syndrome (and those of their families and carers) are gathered robustly and that decisions about their care are made collaboratively, based on an individual's needs and wishes.

It is also extremely important people with Down's syndrome have access to speech and language therapy so their eating, drinking and swallowing are fully assessed. Services must also know when to refer to speech and language therapy to ensure dysphagia is identified and managed appropriately.

The RCSLT believes that the following areas could be improved:

- Knowledge and understanding of both the strengths people with Down's syndrome have and the things that they may find challenging, and how much this varies on an individual basis.
- Knowledge and understanding of co-occurring conditions in people with Down's syndrome. Other conditions (including, for example, sensory needs, autism, other learning disabilities, physical or mental health conditions, and dementia) may present differently in people with Down's syndrome. This can lead to diagnostic overshadowing.
- Access to services, especially mental health services, for people with Down's syndrome.
- It is essential that all information is provided in accessible formats. There should also be a focus on ensuring all services are inclusive environments. The Communication Access symbol provides a model of how to deliver this: <https://communication-access.co.uk/>.
- More robust monitoring of health needs for people with Down's syndrome, for example, the monitoring of known conditions.
- Annual health checks for people with learning disabilities could include specific questions for people with Down's syndrome relating to associated health risk, including uptake of COVID-19 vaccines, heart conditions and thyroid conditions.
- The training of staff who may come into contact with people with Down's syndrome.
- Preventative services.
- Services for those people with Down's syndrome who have dementia who may have co-occurring complex health and behaviour support needs.
- Knowledge and recognition that there is a broad range of cognitive and communication difference amongst people with Down's syndrome and services must not be a 'one size fits all' but based on an individual's abilities and needs.

If it would be helpful, we could facilitate contact for departmental officials with the Adult Learning Disability Network made up of speech and language therapists specialising in working with people with learning disabilities.

Do you agree or disagree that the staff at your organisation understand how to support the specific needs of people with Down's syndrome?

- strongly agree
- agree
- disagree
- strongly disagree
- don't know

RCSLT members report a variance in understanding of how to support the specific needs of people with Down's syndrome outside of specialist learning disability services.

Speech and language therapists within learning disability services have considerable understanding of how to support individuals who have Down's syndrome, including supporting their communication and eating, drinking and swallowing needs.

There is also a good understanding amongst other staff in specialist learning disability teams/services, especially where there are specific care pathways in place, of how to support the specific needs of people with Down's syndrome.

However, across wider acute and community services there are often gaps in this understanding. This is particularly the case among professionals who are less likely to come into contact with people with learning disabilities or Down's syndrome. This indicates a training and knowledge gap.

Accessibility (for example, through using Easy Read information and the implementation of reasonable adjustments) should be improved across wider services.

Do you agree or disagree that all staff who provide services or support to people with Down's syndrome, are aware of their legal obligations and duties in providing healthcare services to meet the physical or mental health needs of people with Down's syndrome?

- strongly agree
- agree
- disagree
- strongly disagree
- don't know

While some staff locally are aware of their legal obligations and duties, RCSLT believe there are gaps. The RCSLT recommends increased training and awareness in a range of areas, including in:

- Accessible Information Standard
- Mental Capacity Act (including gaining informed consent, assessing capacity, fluctuating capacity and shared decision making)
- Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)
- Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

In addition, a better understanding of the interface between the Mental Health Act and the Mental Capacity Act is needed.

What would be the most helpful things to include in the guidance for organisations providing services to meet the physical health needs of people with Down's syndrome and their families and carers?

The RCSLT recommends the guidance includes the following:

- As an overarching principle, it must be clear on how services must provide information in an accessible format, in line with the NHS Accessible Information Standard and the RCSLT's [5 Good Communication Standards](#).
- How to provide key information to people with Down's syndrome and their families and carers (for example, how and when to access services) in an appropriate, accessible format (for example, Easy Read).

- How to ensure services are inclusive environments – the Communication Access symbol provides a model of how to deliver this: <https://communication-access.co.uk/>.
- How to robustly monitor and respond to known health conditions among people with Down's syndrome.
- Encouraging baseline assessments to be carried out as standard in line with best practice. For example, screening services to establish people's baseline skills to identify any changes as early as possible to make an effective early diagnosis of dementia so people get the support they need in a timely way.
- Information on physical health risk factors for people with Down's syndrome, including what to ask people during their annual health check.
- Lifelong approach for the person with Down's syndrome, their family and carers, recognising how to support people with Down's syndrome to live well across their life, from early education to employment, advance care planning and end of life care.
- Signposting to both mainstream and specialist services for people with Down's syndrome to maximise quality of life. For example, social opportunities, and health and fitness.

Do you think there are barriers in providing physical health services for people with Down's syndrome?

- Yes
- no

The themes from successive LeDeR reports are well known and documented nationally. The learning from this programme, therefore, informs our submission about the inequalities faced by people with Down's syndrome due to the fact that they have a learning disability:

- [2021 LeDeR report](#)
- [LeDeR annual reports](#)

RCSLT members have identified a number of barriers to providing physical health services for people with Down's syndrome. These include:

- Financial, social and digital poverty.
- Health and care teams lacking appropriate knowledge and skills and a lack of specialist roles.
- A lack of joined-up care resulting from breakdowns in communication across primary, secondary and tertiary services.
- Some people with Down's syndrome may have difficulties communicating pain or distress which can make recognition and diagnosis of illness more challenging This can lead to an unmet need.
- Misdiagnosis, diagnostic overshadowing and poor medical management which can result in higher rates of illness and premature deaths (Heslop et al, 2013).
- Lack of accessibility and reasonable adjustments for people with Down's syndrome.
- Cultural issues, for example, the exclusion of people with Down's syndrome.
- Long-term failings in health and social care workforce planning impacting on staff numbers as well as the levels of knowledge and expertise and a lack of specialist roles.

Are there good practice examples of what works best to meet the physical or mental health needs of people with Down's syndrome you would like to share?

All health services should be making reasonable adjustments for people with learning disabilities irrespective of their condition. So people with Down's syndrome should have equal and inclusive access to services.

RCSLT members have identified that there are examples of good practice across the country. But this is not the case across the whole country. There is local variation.

Examples of good practice include the following.

Integrated care pathways

- Between specialist primary and secondary care services for those known health conditions affecting people with Down's syndrome

Multidisciplinary working

- Multi-disciplinary team pathways
- Dementia pathways for people with learning disabilities or Down's syndrome
- Inclusive provision and pathways for people with learning disabilities who move between acute and community speech and language therapy services

Collaborative working across services

- Between specialist learning disability services and specialist palliative care services in the community
- Between dietetics and speech and language therapy
- Specialist learning disability teams supporting and mental health teams to make reasonable adjustments
- Learning disability specialist clinicians offering training to colleagues in acute services

Ensuring inclusive communication and reasonable adjustments

- Services ensure person-centred care through inclusive communication and reasonable adjustments, including through:
 - using communication and hospital passports
 - providing information in Easy Read format
 - implementing the RCSLT's the RCSLT's [5 Good Communication Standards](#). 5 good communication standards.

Good practice regarding learning disability annual health checks

Do you think people with other genetic conditions benefit from the same health services used to support people with Down's syndrome?

- Yes
- No

RCSLT members report that there is huge variation in levels of understanding and awareness of different genetic conditions.

If there any known health risks related to specific genetic conditions, people should have the right to accessible and inclusive health services tailored to their needs.

While people with other genetic conditions could benefit from the same health services used to support people with Down's syndrome – as could all people with communication and swallowing needs – not all of them do or are currently able to – benefit from those health services.

It is essential, for example, that everyone who has a genetic condition has access to speech and language therapy services at the appropriate level of specialism to identify and meet their communication and swallowing needs.

Speech and language therapists report that Down's syndrome may be better understood than some other rarer conditions and that some people with rarer genetic conditions may face additional health inequalities because their condition is less well recognised and understood.

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

- Yes
- no

All genetic conditions are different, and the same condition can affect individuals in different ways, including Down's syndrome. Care should be person-centred and based on individual needs rather than the diagnosis somebody has received.

However, people with Down's syndrome may be at particular risk of certain physical health issues. These issues may present in different ways to people without Down's syndrome or people with a different genetic condition.

Do you think there are differences in mental health needs of people with Down's syndrome and other genetic conditions?

- Yes
- no

All genetic conditions are different, and the same condition can affect individuals in different ways, including Down's syndrome. Care should be person-centred and based on individual needs rather than the diagnosis somebody has received.

However, as with physical health, people with Down's syndrome may be at particular risk of certain mental health issues. These issues may present in different ways to people without Down's syndrome or people with a different genetic condition. This may be due to social barriers, for example, a lack of social opportunities, a lack of access to services or complex communication needs.

There is a higher incidence of dementia in people with learning disabilities. Adults diagnosed with a learning disability are 5.1 times more likely to have a diagnosis of dementia, and age-related dementia is more common at earlier ages in people who have a learning disability. People with Down's syndrome are at increased risk of early onset Alzheimer's (Public Health England, 2019).

Questions about adult social care

Do you have views on adult social care services providing support to people with Down's syndrome you would like to share?

- Yes
- no

This is an important area because Down's syndrome is a long-term condition. People will need support, beyond healthcare, to live well.

RCSLT members report that there are inconsistencies in the level of, quality of, and access to social care for people with Down's syndrome. This may be due to a lack of adequate funding in some areas.

The RCSLT believes that the following areas could be improved:

- Forward planning, with understanding of how people's needs may change over time and how support needs will change/increase to minimise unnecessary changes to their housing and quality of life
- Ensuring person-centred care planning (with use of appropriate communication support)
- Access to meaningful social opportunities, educational opportunities, and employment opportunities
- Transition between services and at key points in a person's life, for example, leaving education, starting employment
- Access to daytime provisions when residential care is in place (that is, individuals are limited to only the people who they happen to live with, with wider social opportunities and networks not supported by social care)
- Knowledge and skills of the social care workforce working with people with Down's syndrome
- Systems to identify and improve inadequate care

Do you agree or disagree that the staff at your organisation understand how to support the specific needs of people with Down's syndrome?

- strongly agree

- agree
- disagree
- strongly disagree
- don't know

RCSLT members report that knowledge and understanding of how to support the specific needs of people with Down's syndrome varies across social care services.

Many staff are not used to working with people with learning disabilities and do not have the knowledge and awareness needed to work with this population. Many staff in the social care sector do not have access to appropriate and ongoing training.

See previous responses for areas the RCSLT believes could be improved, including through ensuring all services are inclusive communication environments and people with more complex communication needs receiving the support, including from speech and language therapy services, they, their families and carers, and the people working with them require.

Do you agree or disagree that all staff who provide services or support to people with Down's syndrome, are aware of their legal obligations and duties in providing adult social care services to meet the needs of people with Down's syndrome?

- strongly agree
- agree
- disagree
- strongly disagree
- don't know

While some staff may be aware of their legal obligations and duties, RCSLT members report that there are significant gaps. Increased training and awareness are needed in certain areas, including in:

- Accessible Information Standard
- Mental Capacity Act (for example, gaining informed consent, supported decision-making)
- Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)
- Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

What would be the most helpful things to include in the guidance for those organisations providing adult social care services to people with Down's syndrome and their families and carers?

The RCSLT recommends that the guidance includes the following:

- As an overarching principle, it must be clear on how services must provide information in an accessible format, in line with the NHS Accessible Information Standard and the RCSLT's [5 Good Communication Standards](#).
- How to provide key information to people with Down's syndrome and their families and carers (for example, how and when to access services) in an appropriate, accessible format (for example, Easy Read).
- How to ensure services are inclusive environments – the Communication Access symbol provides a model of how to deliver this: <https://communication-access.co.uk/>.
- How to identify soft signs of deterioration, for example, through the use of physical deterioration and escalation tools such as RESTORE2.
- How to ensure potential dysphagia is identified and referrals to speech and language therapy for eating, drinking and swallowing assessments.
- Ensure people have access to ongoing access to speech and language therapy throughout their lives if their needs change, both communication and swallowing.
- How to robustly monitor and respond to known health conditions among people with Down's syndrome.

- How to robustly monitor and review the care and support needs of people with Down's syndrome, ensuring that the individual's preferences are central to this decision-making.
- Encouraging baseline assessments to be carried out as standard in line with best practice. For example, screening services to establish people's baseline skills to identify any changes as early as possible to make an effective early diagnosis of dementia so people get the support they need in a timely way.
- Information on physical health risk factors for people with Down's syndrome, including what to ask people during their annual health check.
- Lifelong approach for the person with Down's syndrome, their family and carers, recognising how to support people with Down's syndrome to live well across their life, from early education to employment, advance care planning and end of life care.
- Increasing awareness of the variety of skills and capabilities of people with Down's syndrome and signposting to both mainstream and specialist services for people with Down's syndrome to maximise quality of life. For example, social opportunities, and health and fitness.
- Increased awareness of the incidence and prevalence of dementia/ Alzheimer's disease among people with Down's syndrome and then need to view these holistically.

Do you think there are barriers in providing adult social care services for people with Down's syndrome?

- Yes
- no

RCSLT members have identified various barriers in providing adult social care services for people with Down's syndrome. These include:

- Financial, social and digital poverty.
- Lack of staff with appropriate knowledge/skills (for example, lack of understanding/ awareness of the variety of skills and capabilities of people with Down's syndrome, or the increased incidence and prevalence of dementia /Alzheimer's disease).
- Lack of joined up care due to a lack of effective communication across primary, secondary and tertiary services.
- Lack of inclusive environments, accessibility and reasonable adjustments for people with Down's syndrome.
- Lack of social opportunities for people with Down's syndrome to reduce social isolation risk.
- Cultural issues, for example, exclusion of people with learning disabilities (including Down's syndrome).

Specialist accommodation for younger people with dementia who may also have complex health and behaviour support needs, including those with Down's syndrome who are at greater risk of developing dementia at an earlier age.

Are there good practice examples of what works best to meet the adult social care needs of people with Down's syndrome you would like to share?

There are some examples of good practice among professionals having awareness of augmentative and alternative communication (AAC) and using varied communication strategies.

There are good practice examples of joint working between different professionals (for example, social workers and occupational therapists) to meet the environmental needs of individuals and future planning.

Embedding the RCSLT's [5 Good Communication Standards](#) and NHS Accessible Information Standard in practice.

Do you think people with other genetic conditions benefit from the same adult social care services used to support people with Down's syndrome?

- Yes

- No

We have left this blank as RCSLT members report that there is huge variation in levels of understanding and awareness of different genetic conditions. Down's syndrome may be better understood than some rarer conditions.

Many social care services are available for people with learning disabilities, and this does not depend on which condition the person has.

Do you think there are differences in adult social care needs of people with Down's syndrome and other genetic conditions?

- Yes
- No

All genetic conditions are different, and the same condition can affect individuals in different ways, including Down's syndrome. Care should be person-centred and based on individual needs rather than the diagnosis somebody has received.

However, people with Down's syndrome may be at particular risk of certain health issues and these issues may present in different ways to people without Down's syndrome or people with a different genetic condition. These health issues will directly impact their adult social care needs.

Questions about housing

Do you have views on housing services providing support to people with Down's syndrome you would like to share?

- Yes
- no

RCSLT members report that that there is a lack of bespoke housing assessments for people with learning disabilities (including Down's syndrome). There is often a lack of social opportunities for people with Down's syndrome within housing environments. This increases the risk of social isolation.

Specialist accommodation is required for younger people who have Down's syndrome and dementia as some of people may also have complex co-occurring health and behaviour support needs.

Do you agree or disagree that local councils understand the need for specialist housing in their local area?

- strongly agree
- agree
- disagree
- strongly disagree
- don't know

RCSLT members report that there is often a lack of understanding among local authority commissioners of the needs of people with Down's syndrome. This is in relation to both their physical and mental health needs and the related impact on their social care and other support needs.

Members tell us that local authorities do not make use of the specialist skills and knowledge of expert clinicians, such as speech and language therapists, and do not recognise the need for robust specialist placements and providers.

Do you agree or disagree that local councils understand the need for integrated approaches to deliver housing with health and social care?

- strongly agree
- agree

- disagree
- strongly disagree
- don't know

The RCSLT does not believe that all local councils understand the need for integrated approaches to deliver housing with health and social care, and they do not all make use of the specialist skills and knowledge of expert clinicians.

Do you agree or disagree that the staff at your organisation understand how to support the specific needs of people with Down's syndrome?

- strongly agree
- agree
- disagree
- strongly disagree
- don't know

As per previous responses, RCSLT members report that not all staff working in housing services and local authorities understand how to support the specific needs of people with Down's syndrome.

What would be the most helpful things to include in the guidance for those organisations providing housing support services to people with Down's syndrome and their families and carers?

The RCSLT recommends that this guidance includes information on:

- how to work with people with Down's syndrome to facilitate their wishes and feelings to ensure that their housing meets their individual needs and preferences.
- how to ensure that all information is provided in an accessible format, in line with the RCSLT's [5 Good Communication Standards](#) and the NHS Accessible Information Standard.

Do you think there are barriers in providing housing support services for people with Down's syndrome?

- Yes
- No

RCSLT members have identified various barriers in providing housing support services for people with Down's syndrome. These include:

- Financial, social and digital poverty.
- Lack of staff with appropriate knowledge and skills, including, for example, a lack of understanding of the strengths of people with Down's syndrome and their support needs and how to communicate with them to make joint decisions about their housing.

These are barriers that people with other learning disabilities also face.

Are there good practice examples of what works best to meet the housing support needs of people with Down's syndrome you would like to share?

N/A

Questions about education and children's social care

Are there good practice examples of what works best to meet the education needs of children and young people with Down's syndrome you would like to share?

For more on the support available to children and young people, including what the RCSLT thinks needs to happen so they get the right support, in the right place, at the right time, please see our

response to the Department for Education's SEND review consultation and the joint RCSLT and ASLTIP policy statement. Both are accessible: <https://www.rcslt.org/news/getting-it-right-for-communication-rcslt-response-to-send-green-paper/>.

How can schools, colleges, local authorities and other organisations further support young people with Down's syndrome to prepare for adulthood, including employment?

N/A

Are there good practice examples of what works best to meet the social care needs of children and young people with Down's syndrome you would like to share?

N/A

Are there good practice examples of what works best to support children and young people with Down's syndrome who are in contact with youth offending teams you would like to share?

If it would be helpful, we could facilitate contact for officials with the Speech and Language Therapy Criminal Justice and Secure Settings Clinical Excellence Network to discuss these issues further.

Questions about the Down Syndrome Act guidance

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

The RCSLT recommends that justice and secure settings should be included in this guidance. This includes, for example, prisons and secure services for children and adults including Child and Adolescent Mental Health Services (CAMHS).

Wider public services also need to be aware of the abilities and needs of people with Down's syndrome, for example, employment services.

Are there good practice examples of other public services that are meeting the needs of people with Down's syndrome you would like to share?

N/A

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

Yes. The RCSLT believes that more could be done to support professionals to understand the needs of people with Down's syndrome, including through:

- Robust training programmes for staff across all health and social care services working with people with Down's syndrome, a learning disability or other genetic condition (including competency frameworks) including about communication and eating, drinking and swallowing.
- National guidance on the known specific health conditions associated with Down's syndrome.
- A series of NHSE and DHSC-run webinars, or other events, to upskill staff using Royal Colleges and professional bodies to develop and share material on people with Down's syndrome. The inclusion of people with Down's syndrome in the development of any training resources and materials.
- Annual health checks for people with learning disabilities should include specific questions for people with Down's syndrome relating to associated health risks.