

Needs Assessment Supporter's Guidelines

February 2023

Needs Assessment Supporter's Guidelines: using the My Social Care Assessment Booklet and the Supporter's Booklet – In England

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How will the My Social Care Assessment Booklet and the Supporter's Booklet help?

The local authority may have their own method to gather information about a person's needs in order to carry out a Needs Assessment. However, they must consider all relevant information provided to them – this means you can provide information in a format that you choose. This is particularly relevant for a person who has Down's syndrome, as the usual format a local authority use to undertake a Needs Assessment may not be suitable in meeting the person's communication needs. The resources in the Supporter's Booklet and in the My Social Care Assessment Booklet for people who have Down's syndrome may help with this.

These resources have been designed to:

- **Help people who have Down's syndrome express their wishes, preferences and outcomes in relation to their day-to-day lives and their hopes for the future**
- **Help supporters to provide information about the assessed person's needs in a way that will be easy for local authorities to understand**

The resources do this by providing a framework that will help express the assessed person's wishes, preferences, outcomes and needs in relation to the eligibility criteria that local authorities must assess people against. This factsheet also provides a set of guidelines to help supporters understand how to use the resources.

It is important to note that the local authority has flexibility in determining which services it would provide to meet assessed eligible needs.

We hope these resources help people to work closely with the local authority in identifying the person's needs, wishes and aspirations and in planning the support that best meets their individual needs



Guidelines

The guidelines will lead you in thinking about the things it might be necessary for the local authority to know about the assessed person and their situation.

Whilst the local authority, during the assessment stage, may capture information about the support others provide to the supported person, this information **must not influence the eligibility determination**. This means the whole of the person's needs must be considered when determining whether the person has eligible needs and, if they do, which of their 'outcomes' they are eligible to receive support with. This is known as a 'carer blind assessment' - that is, it disregards any support a person receives from family or other people, even if this support will continue following the assessment. It is therefore important to highlight **all of the person's needs**.

Significant Impact

It is important that you consider, what the term 'significant impact' might mean in relation to the wellbeing of the individual person who has Down's syndrome about whom you are gathering information. What would be the negative impact upon the person of outcomes not being met?

Once an assessment has taken place, the local authority must determine whether a person is eligible for care and support.

A person will have eligible needs if they meet all of the following:

- they have care and support needs as a result of a physical or a mental condition
- because of those needs, they cannot achieve two or more of the outcomes specified
- as a result, there is a significant impact on their wellbeing

There is not a precise definition of what significant impact means in the [Care and Support Statutory Guidance](#) but it does say that local authorities must consider:

'whether the adult's needs and their consequent inability to achieve the relevant outcomes will have an important, consequential effect on their daily lives, their independence and their wellbeing'

And that

'Needs may affect different people differently, because what is important to the individual's wellbeing may not be the same in all cases. Circumstances which create a significant impact on the wellbeing of one individual may not have the same effect on another'

[SCIE Guidance](#) suggests that 'significant impact' could be a consequence of:

- a single effect: this means that the inability to achieve two or more outcomes affects at least one of the areas of wellbeing in a significant way.
- a cumulative effect: this means that the individual may have needs across several of the eligibility outcomes, perhaps at a relatively low level, but as these needs affect the individual in various areas of their life, the overall impact on the individual is significant.
- a domino effect: this means that currently the individual may have needs in relation to few eligibility outcomes, but it can be anticipated that in the near future other outcomes will be affected, causing a significant impact on the individual's wellbeing.

After the assessment the local authority must write to the assessed person to advise them of their eligible needs. After this the care and support planning stage should begin. This is when the local authority should work with the assessed person to decide how their eligible needs will be addressed- if the assessed person agrees, at this point, family and friends can say what they are willing to do to support the person. It is important to note that whilst assessed eligible needs must be met, the local authority has flexibility in determining which services it would provide to meet these needs.

We advise supporting the assessed person to complete their My Social Care Assessment Booklet in small manageable chunks rather than completing it in one go as this is likely to be overwhelming. We would suggest the same strategy for completing the Supporter's Booklet.

Where do I start?

1. Support the assessed person to complete their My Social Care Assessment Booklet. Help them to record:

- **All the goals (outcomes) they wish to achieve under each eligibility criteria - Outcomes are things the person needs or wants to achieve that are difficult or impossible to achieve without support.**
- **The support they feel they need and would like to achieve these outcomes**

Remember to help the person record how often they need particular support and if there are particular ways or times of day they need this support.

Most local authorities are only providing care and support to people to help them meet specific outcomes as identified through their assessment. Therefore it is important to remember to support the person to record each individual outcome they wish/need to achieve under eligibility criteria A-J as these, if agreed as eligible, will define the care and support the person will be provided.

2. Use the guide below to complete the Supporter's Booklet

If you feel you might struggle to explain the things the person being assessed needs support with, complete a daily diary for a week, detailing all the things you (and others) do to support the person. There is a resource to help with this in the Supporter's Booklet.

What are the different sections of the Supporter's Booklet for?

The Supporter's Booklet has an individual page for each of the ten eligibility criteria – see example below. Not all the eligibility criteria will be relevant for everyone. If there are some that are not relevant, leave them blank.

There is a continuation page at the end of the Supporter's Booklet if additional space is required.

Supporters Booklet

Eligibility criteria		A. Managing and maintaining nutrition
Outcomes assessed person <u>wishes</u> to achieve		1. Outcomes assessed person <u>wishes</u> to achieve under this criteria.
Outcomes assessed person <u>needs</u> to achieve		2. Outcomes assessed person <u>needs</u> to achieve under this criteria.
<p>Is the person able to achieve these outcomes without support?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p>Unable means, unable to achieve without assistance, significant pain, distress or anxiety or without taking significantly longer than would normally be expected or without endangering their health / safety or that of others.</p> <p>Remember to mention whether the person needs: prompting, direct physical care and support and / or emotional support.</p>	Notes about support required	
<p>The effect not being able to achieve the eligibility criteria and outcomes is likely to have on person's <u>wellbeing</u> and how providing support to meet these outcomes is likely to <u>prevent, reduce or delay</u> further needs from developing.</p>		

Filling out the Supporter's Booklet

Box 1. Outcomes assessed person wishes to achieve

Transfer the outcomes the assessed person has identified in their My Social Care Assessment Booklet to the matching eligibility pages of the Supporter's Booklet. Make sure this is recorded in the 'Outcomes assessed person wishes to achieve' section. It may be helpful to look at the example outcomes on the next page.

Box 2. Outcomes assessed person needs to achieve

Alongside the outcomes the assessed person wishes to achieve, it is important to highlight the outcomes they need to achieve. For example, a person who needs support preparing meals might wish to have support to make a hot meal once a month but it is likely they will need support to prepare meals more frequently than this to 'manage and maintain their nutrition'. This section is for supporters to provide further outcomes a person needs to achieve.

Outcomes are things the person needs or wants to achieve that are difficult or impossible to achieve without support. It may help to look at the 'Notes about support required' section below first, so you can make sure the outcomes address the challenges you have identified under each eligibility criteria.

Outcomes should not make reference to who will help the person achieve the task or activity, as this should be considered after the local authority has informed the assessed person if they have eligible needs. See example outcomes below – whether the outcome is identified by the assessed person or the supporter will determine which section of the form it appears in (outcomes the person needs or wants to achieve).

Example outcomes

Eligibility criteria A: Managing and maintaining nutrition

- To ensure appropriate food intake daily (breakfast, lunch and dinner)
- To ensure enough fluids are consumed daily
- To manage a budget for food related expenditure
- To shop for food once a week
- To communicate with shop keepers when out shopping
- To handle money safely
- To build independence around knowing which foods will maintain a healthy balanced diet
- To build independence around knowing what portion sizes of different foods are healthy
- To be involved in preparing and cooking a hot meal each evening

Eligibility criteria F: Maintaining a habitable home

- To check whether the bathroom needs cleaning daily and to clean it when necessary
- To dust and vacuum the house once a week
- To do the washing up after every meal
- To maintain the garden and cut the grass weekly
- To manage household bills and budget for these
- To maintain tenancy agreement
- To manage rent payments and budget for this
- To ensure essential amenities and domestic appliances are maintained
- To ensure annual safety checks are arranged and carried out

Eligibility criteria G: Developing and maintaining family or other personal relationships

- To meet friends once a week
- To live close enough to grandparents to be able to walk there
- To visit grandparents on a Sunday
- To maintain friendships at work and at the leisure centre

Eligibility criteria H: Accessing and engaging in work, training, education or volunteering

- To maintain employment on a Tuesday and Thursday

Box 3. Notes about support required

Under each eligibility criteria the person has needs for care and support, it is necessary to provide information about their [circumstances](#) and [why they need support](#) to achieve their outcomes.

The knowledge you have of the person and their circumstances will be valuable to the assessor as [you know the person best](#). The material in the table below is designed to help you think about the information the assessment should capture in relation to the support the person needs to achieve their outcomes. Use this as a prompt about factors you may need to consider when filling out box three of the Supporter's Booklet.

Eligibility criteria

Considerations

A

Managing and maintaining nutrition

Preparing food and drink

What support does the person need to prepare / cook:

- Breakfast?
- Snacks?
- Lunch?
- Dinner?

Can the person prepare some foods but not others? For example, some people can make sandwiches and use the microwave but are unable to make a full cooked meal without support.

Can the person make hot and cold drinks independently? If not, what support do they need? For example, regular prompting or physical support?

Eating and drinking

- Is the person able to ensure they drink an appropriate amount of fluid throughout the day? Does the person need physical support or prompting to drink the right amount of fluids?

Does the person know when it is time for particular meals or would they need support or prompting from others?

Does the person:

- Need physical support to eat?
- Need a particular diet due to allergies or swallowing problems?
- Need food cut up small or blended?

The person should have had a [speech and language therapy assessment](#) if there are swallowing concerns – this assessment should be provided to the assessor.

Diet and portion size

Does the person understand how to manage a healthy diet and the risks of not doing so?

Remember, people are entitled to make what others may deem, unwise decisions if they understand the risks and consequences of making a particular decision.

Many people will need support to understand the risks and consequences around food choices and may need encouragement to make healthy choices.



Eligibility criteria

Considerations

B

Maintaining personal hygiene

Personal Hygiene

Does the person:

- Understand how frequently they need to wash?
- Understand the consequences and risks of not maintaining their hygiene?
- Have the ability to wash themselves effectively?
- Have any physical issues that prevent them from reaching to wash themselves all over?
- Have the ability to use the bath or shower alone without undue slipping or drowning risks?
- Have any medical reasons they might be more at risk in the bathroom, for example epilepsy?
- Shave? Can they do this independently? Are there undue risks the person may hurt themselves?
- Know how frequently they need to brush their teeth? Can they reach all the areas they need to when brushing their teeth and would they know how long to brush for?

Laundry

Does the person understand how frequently they need to change and wash their clothes and bedding?

Can the person:

- Use the washing machine?
- Safely use washing detergent?
- Understand how to dry their clothes?
- Understand their laundry needs to be properly dry before being put away?
- Use the iron safely- is there an undue risk of burns?

C

Managing toilet needs

Contenance

Is the person able to use the toilet independently? Can they reach the toilet in time? Are there any factors, such as, mobility, physical needs or the extent of the person's learning disability that impact their ability to manage this independently?

Does the person need an accessible toilet? If so what impact does this have on them and their ability to access the community and local facilities?

If the person was unwell, might they need more support to manage their toileting needs than they would otherwise?

Eligibility criteria

Considerations

D

Being appropriately clothed

Choosing appropriate clothes

Is the person able to understand what clothing is appropriate for different situations or weather conditions? For example, would the person:

- Know to wear a coat in cold weather or to take off a jumper if they were too hot?
- Know to wear a sun hat or use sun cream in hot sunny weather?

Remember people have the right to wear clothes others may not approve of, if they have capacity. For example, if the person is able to understand the risks and consequences of going out without a coat in cold weather, they have the right to make this choice.

Also consider whether:

- The person understands when their clothes are dirty or worn out and need changing/replacing

Can the person:

- Purchase new clothes when necessary? Would they be able to manage this independently or would they need support?

Dressing

Can the person dress themselves? Are there some clothes they can manage to put on independently but others they cannot? For example, does the person have difficulty with doing up buttons, zips or other fasteners, but manage ok with more casual clothes?

E

Being able to make use of the adult's home safely

Household items / activities

Are there any risks around the person's use of household items?

Consider the person's ability to use:

- The heating / gas appliances
- Electrical equipment

Using the bathroom

Is the person able to safely use the toilet / shower / bath independently?

Does the person:

- Face a risk of scalds or burns due to their level of understanding of temperature?
- Have any medical conditions that make using the bathroom riskier? For example, epilepsy may present a risk of drowning and may mean the person needs 1:1 supervision when bathing.
- Have the ability to use the shower without undue risk of slipping or falling?

Using the kitchen and food hygiene

Are there any risks around the person's use of the kitchen?

Consider:

- Sharp equipment
- Hot and / or gas appliances
- Electrical equipment
- The person's level of understanding about the dangers posed by leaving the cooker or oven on or through water mixing with electrical equipment

Eligibility criteria

Considerations

E

Being able to make use of the adult's home safely

Consider the person's level of understanding about food hygiene and cross contamination.

Would the person know:

- To clean surfaces and equipment properly to ensure contamination and food poisoning does not occur?
- How long to cook different foods to ensure they are cooked properly?
- How to store left over food?
- How to identify food that is past its use by date?

Mobility

Does the person:

- Have any mobility issues affecting their ability to move about their home or get out of bed?
- Have any medical issues that might make using certain areas of the home riskier, for example, epilepsy or dementia?
- Have steps or other obstacles to access their home that they struggle with?

Emergency situations

Consider whether the person would know what to do in the event of a fire or flood. Would they know:

- How to contact the emergency services?
- Where to safely wait for emergency services to arrive?

F

Maintaining a habitable home

Managing the home

Can the person:

- Understand the consequences and risks of not maintaining a habitable home environment?
- Recognise when their home needs to be cleaned?
- Sustain their home to a habitable level?
- Clean and Hoover their home independently?
- Use appliances such as the Hoover safely?
- Use cleaning products safely? Are there any chemical burn or health hazards the person would not be able to mitigate when using domestic cleaning products?
- Manage their finances and pay their rent or mortgage?
- Maintain amenities and pay for these?

Would the person need support to arrange and pay for any essential works that might be necessary within the home, or contact their landlord to arrange this?

Eligibility criteria	Considerations
<p>G</p> <p>Developing and maintaining family or other personal relationships</p>	<p>Does the person:</p> <ul style="list-style-type: none"> • Have any communication needs that mean they need support to maintain or make friendships and/or maintain relationships with family? • Have the ability to leave their home safely? • Have the means and ability to travel to visit friends and family to maintain these relationships? • Have the ability to use, a phone or computer to organise meeting with friends and relatives?
<p>H</p> <p>Accessing and engaging in work, training, education or volunteering</p>	<p>Does the person have a work, training, education or volunteer placement (or a desire to engage in these activities) that they need support to maintain?</p> <ul style="list-style-type: none"> • Does the person need support to: • Access information about opportunities? • Organise and plan their involvement in these activities? • Understand the time so as to make it to these engagements on time? • Travel to or physically access facilities to enable participation in the relevant activities? • Physical support to participate in these activities?
<p>I</p> <p>Making use of necessary facilities or services in the local community including public transport, and recreational facilities or services</p>	<p>Accessing social and leisure activities and community services</p> <p>Think about the person’s ability to plan, make unaccompanied trips and use public transport.</p> <p>Would the person be safe if they left the house alone? Are there any issues around absconding - would the person be at risk if they did so? Are there any measures that need to be taken to avoid the person putting themselves in danger?</p> <p>Does the person:</p> <ul style="list-style-type: none"> • Have the ability to use public transport independently (assuming public transport is an option where they live – if not what other alternatives do they need – taxi’s, lifts from friends and family etc.)? • Have the ability to travel into the community to access local facilities and access shops, the bank, educational/work and leisure facilities? • Have the ability to manage their money safely? • Have a trusting nature - does this mean they are at risk of coercion, abuse or exploitation? • Have an understanding about the risks posed by traffic

Eligibility criteria	Considerations
<p>I cont'd</p> <p>Making use of necessary facilities or services in the local community including public transport, and recreational facilities or services</p>	<p>Physical Health</p> <p>Adults who have Down’s syndrome are entitled to a free Annual Health Check with a GP. The assessment should capture any needs a person has regarding attending this annual appointment as well as accessing any emergency healthcare that may be necessary.</p> <p>Can the person:</p> <ul style="list-style-type: none"> • Voice feeling unwell and explain their symptoms? • Go to the pharmacist to ask for advice? • Attend A&E in an emergency? • Make an appointment with their GP without prompting or support? • Remember to attend a GP appointment without prompting or support? • Understand the time so as to get to their appointment on time? • Tell the GP about their health without support? • Ask the GP to explain their health issues in an accessible manner? (e.g. through using easy read resources) • Remember the advice that is given and follow it? • Take a prescription for medication to the chemist? • Manage their medication? <p>DSA health resources can be found here:</p> <p>About Down's Syndrome.</p>
<p>J</p> <p>Carrying out any caring responsibilities the adult has for a child</p>	<p>Does the person have any parenting or other caring responsibilities? If so, what support do they need with this?</p> <p>People who have Down’s syndrome are increasingly taking on caring responsibilities for their ageing parents.</p> <p>If the person has needs as a carer do they need a separate Carer’s Assessment? If so, make sure to request this in writing.</p> <p>Does the person they are caring for need a Needs Assessment of their own? If so, make sure to request this in writing.</p>

It may also help to provide the assessor, and any other professionals involved in providing evidence, with information about the learning and health profile of people who have Down’s syndrome. You will find lots of relevant information at DSA’s website www.downs-syndrome.org.uk . You can also call the Helpline **0333 1212 300** for information.

Box 4. Wellbeing

A person's needs for care and support will affect their wellbeing in different ways. It is important to highlight how a person's individual wellbeing is likely to be affected if they do not receive the support they need to achieve their own outcomes.

Use the points below when explaining how the assessed person's wellbeing is likely to be affected if they are not provided support to meet their outcomes.

Wellbeing is defined under the Care Act (2014) in relation to a person's:

- Personal dignity (including treatment of the individual with respect) Physical and mental health and emotional wellbeing
- Protection from abuse and neglect
- Control over day to day life (including over care and support and how this is provided)
- Participation in work, education training or recreation
- Social and economic wellbeing
- Domestic, family, and personal relationships
- Suitability of living accommodation
- Contribution to society

The local authority must also consider how the provision of information, advice or support would **prevent, reduce or delay** a person's needs from developing further.

It may therefore help to describe how the provision of support to enable the person to achieve their outcomes, is likely to prevent, reduce or delay their needs for care for support from developing, or, how their needs are likely to increase if they do not receive support.

Wellbeing will be affected in different ways for different people; therefore the wellbeing illustrations below are purely examples of how James' individual wellbeing may be affected if support is not provided to achieve his outcomes.

Wellbeing examples

Eligibility criteria E: Being able to make use of the adult's home safely

James would be unable to use the kitchen safely and would be unable to cook and store food safely or follow use by dates. He would be unable to maintain a germ-free environment in the kitchen and bathroom - this may put his health at risk.

James would be unable to leave his home in the case of a fire or other emergency and would be unable to raise the alarm with emergency services. This would put James' safety at risk and he would be at risk of neglect. James would lose control over his day to day life; this is likely to detrimentally affect his mental health and emotional wellbeing and lead to an increase in support needs.

Wellbeing examples

Eligibility criteria G: Developing and maintaining family or other personal relationships

James would be unable to maintain relationships with friends and family. This would likely lead to a decline in social wellbeing and have a detrimental effect on his mental health and emotional wellbeing. This is likely to lead to an increase in support needs.

Eligibility criteria I: Making use of necessary facilities or services in the local community including public transport, and recreational facilities or services

James has a trusting nature and without support in the community is likely to be exploited by others. James would be at risk of neglect and unable to access medical treatment. James would become socially isolated. It is likely this would adversely affect his emotional wellbeing and have a detrimental effect on his mental and physical health. James would be unable to maintain his personal relationships and would lose control over his day-to-day life.

The impact of the person's needs on people involved in caring for them

What impact does the person's needs have on others in the household? Are there children who are affected by the person's needs or perhaps elderly grandparents or parents?

If other people are affected by the person's needs remember to explain how they are affected and whether there is anything that the local authority could do to help this situation.

Is there anything the local authority could do to support the main carer to continue in their caring role for the assessed person (assuming the assessed person is happy to continue to be cared for by the main carer)?

Might a [Carer's Assessment](#) help? This could lead to support or services for the carer to enable them to continue in their caring role.

[See our Asking for a Carers Assessment Factsheet.](#)

What should happen next?

The professional undertaking the assessment should have the necessary [skills knowledge, competence and appropriate training](#) to carry out the assessment.

The assessment is subject to professional discretion. This means the professional assessing the person's needs is able to use their [professional judgement](#) to determine what the person's needs are and the support the person needs to meet their needs. This means the assessor may offer to meet a person's needs in an alternative way to the way the person wishes.

However the assessor must also [consult a person who has expertise in relation to Down's syndrome](#) – this is likely to be the person's GP. You may have already asked the GP to provide information for this purpose. If you have not, it is likely to be appropriate for the assessor to ask the person's GP for their input.

You may like to provide the assessor with information about the learning and health profile of people who have Down's syndrome. You will find relevant information at DSA's website www.downs-syndrome.org.uk. You can also call the Helpline Tel: 0333 1212 300 for information.

The assessor must take all relevant information provided during the assessment process into account. They must use this information to decide whether the person is eligible for care or support to meet their outcomes.

The assessor must **disregard any support the person is currently receiving when making a determination about eligibility**.

Make sure the assessor provides a **written explanation** about the outcomes they deem the person is eligible to receive support to meet. If any outcomes are deemed not eligible for care or support, the assessor must **clearly explain in writing** their reasons for making this determination.

They must also provide information about:

- What could be done to reduce the person's needs
- Relevant services in the person's locality that may help to prevent, reduce or delay the person's needs from developing further

More information

[Housing and Social Care Support for Adults: Housing & Support For Adults - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk/)

[Making everyday decisions post 16: Making-Decisions-post16.pdf \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk/)

[Lasting Power of Attorney: LPA-Factsheet .pdf \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk/)

If you have any questions about assessments please call the Down's Syndrome Association Helpline on 0333 1212 300 or email info@downs-syndrome.org.uk

Support organisations for carers

Carers UK

Provides information, advice and support for carers and campaigns to improve carer's lives: www.carersuk.org

Carers Trust

Work to improve services, support and recognition for carers. They provide information, forums, and search tools to help find local carers services: www.carers.org

Other useful resources

Health and social care law: information and draft letters for making a complaint to the local authority

<http://www.irwinmitchell.com/personal/protecting-your-rights/social-healthcare-law/the-care-act/care-act-factsheets-and-template-letters>

NHS information on assessments

[nhs.uk/CarersDirect/guide/assessments/Pages/Overview.aspx](https://www.nhs.uk/CarersDirect/guide/assessments/Pages/Overview.aspx)

Social Care Institute for Excellence assessment and eligibility information

[scie.org.uk/care-act-2014/assessment-and-eligibility/](https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/)

Social Care Institute for Excellence assessment and eligibility process map

[scie.org.uk/care-act-2014/assessment-and-eligibility/process-map/index.asp](https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/process-map/index.asp)

The Local Government Ombudsman

lgo.org.uk

Government guidance and legislation

Statutory guidance to support local authorities implement the Care Act 2014 (2017)

gov.uk/guidance/care-and-support-statutory-guidance

The Care Act (2014)

legislation.gov.uk/ukpga/2014/23/contents/enacted

The Care and Support (Assessment) Regulations 2014

legislation.gov.uk/uksi/2014/2827/pdfs/uksi_20142827_en.pdf

The Care and Support (Eligibility Criteria) Regulations 2015

legislation.gov.uk/uksi/2015/313/pdfs/uksi_20150313_en.pdf

The Mental Capacity Act (2005)

legislation.gov.uk/ukpga/2005/9/contents

The Mental Capacity Code of Practice (2007)

gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf



If you would like further information about social care assessments please do get in touch.

DSA helpline:

0333 1212 300 | 10am-4pm

info@downs-syndrome.org.uk