DSUK
Down Syndrome UK

Future Pathways

The Care Act Outcomes: A Guide for Parents of Young People and Adults with Down Syndrome



Introduction

This guide helps parents prepare for a Care Act needs assessment by thinking through each of the ten eligibility outcomes, one at a time, for their son or daughter with Down syndrome.
Under the Care Act 2014, local authorities in England use ten "outcomes" to decide whether an adult has eligible care and support needs. The assessor will look at what your young person or adult can do, what they struggle with, and what support they currently receive — including the support you give at home without thinking about it.

Families often know their son or daughter so well that the support they provide has become invisible. This guide is designed to make it visible again, so the assessment reflects real day-to-day life rather than a "good day" snapshot.

How to use this guide

- **Work through one outcome at a time**. You do not need to complete it in one sitting.
- **Jot down real examples as you go** — specific examples are far more useful to an assessor than general statements.
- **Involve your son or daughter as much as possible**. Their views, wishes and goals matter and should be at the centre of the assessment.
- **Think about a typical week**, including bad days, not just what happens when everything goes well.
- **Ask other people who know them well**, such as siblings, college staff, support workers or day service staff.
- **Bring your notes to the assessment**, or send them to the assessor beforehand.

Important: this guide covers England only
This guide is based on the Care Act 2014 and the SEND Code of Practice, which apply in **England only**. Social care and education law are **different in Wales, Scotland and Northern Ireland**. Separate guides for those nations are being produced. If you live outside England, please don't rely on this guide.
The examples in this guide are typical situations, not real people.

Please read: this is not financial or legal advice. This guide is general information, shared in good faith by parents and Down Syndrome UK from our own experience and research. Rules and figures change, and every family's situation is different. Always check with the right organisation, and take professional advice, before making decisions.

Understanding eligibility

An adult has eligible needs when three conditions are all met.

1. Their needs arise from, or are related to, a physical or mental impairment or illness. Down syndrome and any associated health conditions meet this condition.
2. As a result, they are unable to achieve two or more of the ten outcomes listed below.
3. As a consequence, there is, or is likely to be, a significant impact on their wellbeing.

The ten outcomes

1. Managing and maintaining nutrition
2. Maintaining personal hygiene
3. Managing toilet needs
4. Being appropriately clothed
5. Being able to make use of the home safely
6. Maintaining a habitable home environment
7. Developing and maintaining family or other personal relationships
8. Accessing and engaging in work, training, education or volunteering
9. Making use of necessary facilities or services in the local community, including public transport and recreational facilities or services
10. Carrying out any caring responsibilities for a child

What "unable to achieve" really means

This is one of the most important points in this guide. A person is treated as unable to achieve an outcome if they:

- **cannot do it without assistance** — and assistance includes prompting, reminding, encouragement, supervision and checking, not only hands-on help;
- **can do it without assistance, but doing so causes significant pain, distress or anxiety**;
- **can do it without assistance, but doing so endangers, or is likely to endanger, their own or someone else's health or safety**; or
- **can do it without assistance, but it takes significantly longer than would normally be expected**.

So "he can do it" is never the full answer. The real questions are: can he do it without anyone helping, prompting or checking; safely; without distress; in a reasonable time; and consistently?

Wellbeing

The Care Act puts wellbeing at the centre of assessment. Wellbeing includes personal dignity, physical and mental health, emotional wellbeing, protection from abuse and neglect, control over day-to-day life, participation in work, education, training or recreation, social and economic wellbeing, domestic, family and personal relationships, suitability of living accommodation, and the person's contribution to society. Think about how difficulties with each outcome affect these areas.

Things to keep in mind for people with Down syndrome

- **A wish to please**. Many people with Down syndrome are keen to please and may answer "yes" to questions such as "Can you cook?" even when they need a lot of help. Assessors should ask open questions and check answers with people who know them well.

- **Processing time**. Extra time to process information and respond is common. Rushed questions can lead to inaccurate answers.

- **Strong routines**. Familiar routines can mask difficulties. A person may manage well in a known setting but struggle when anything changes.

- **Health conditions**. Conditions more common in Down syndrome — such as thyroid problems, hearing and sight difficulties, sleep apnoea, coeliac disease, heart conditions and, in later adulthood, an increased risk of dementia — can affect ability and may change over time.

- **Fluctuating ability.** Tiredness, anxiety, illness or a change of routine can make a big difference. The assessment should consider needs over a period of time, not just a single day.

- **Learning versus doing**. Being able to do a task when taught, prompted or supervised is not the same as doing it independently and consistently in everyday life.



Outcome 1: Managing and maintaining nutrition



What does this mean?

The Care Act considers whether a person can access food and drink, and prepare and eat a reasonably balanced diet, to stay healthy.

This is much broader than simply "cooking a meal". It includes the ability to:

- Plan meals and decide what to eat.
- Shop for food, or arrange for food to be bought.
- Store food safely, including using the fridge and freezer correctly.
- Check use-by dates and recognise food that has gone off.
- Prepare simple meals, snacks and drinks.
- Cook safely using a hob, oven or microwave.
- Eat and drink enough, at regular times.
- Make reasonably healthy choices and manage portion sizes.
- Follow any special diet, such as gluten-free for coeliac disease.
- Eat safely, including chewing and swallowing without risk of choking.

The assessment should consider both practical skills and the ability to carry them out consistently.

Why does it matter?

Many people can prepare food when directed or supervised, but may struggle to:

- recognise when they are hungry or thirsty, or when they have had enough
- remember to eat regular meals or drink enough fluids
- plan meals for the week and buy the right ingredients
- prepare food safely and hygienically
- choose a balanced diet rather than relying on snacks or takeaways

People with Down syndrome may have a higher risk of weight gain, thyroid problems, coeliac disease, constipation and swallowing difficulties. Poor nutrition can therefore have a significant impact on their physical health and wellbeing.

Questions to consider

Planning and shopping

Can they:

- decide what to eat and plan meals?
- write or follow a shopping list?
- buy food within a budget?
- choose healthy options?

Do they:

- need someone to plan meals for them?
- buy the same few items every time?
- spend their money on snacks or treats rather than meals?

Storing food

Can they:

- put food away in the right place?
- check use-by dates?
- recognise when food has gone off?
- keep raw and cooked food separate?

Preparing and cooking

Can they:

- make a hot drink safely?
- prepare a cold meal, such as a sandwich or cereal?
- heat a ready meal in the microwave?
- cook a simple hot meal from scratch?
- follow a recipe, picture recipe or video?

Do they:

- need prompting to start?
- need supervision for safety, for example with sharp knives or hot pans?
- know that food must be cooked through?

Eating and drinking

Can they:

- eat regular meals without being reminded?
- drink enough fluids during the day?
- manage portion sizes?
- eat safely without rushing, overfilling their mouth or choking?

Do they:

- have any swallowing difficulties?
- follow a special diet, such as gluten-free?
- need help to cut up food or open packaging?
- eat too much, or too little, without support?

What support might be needed?

Support may include:

- help with meal planning and shopping lists
- online shopping or shopping support
- prompting to eat and drink regularly
- supervision when cooking
- picture recipes and visual meal planners
- batch cooking with support

- help to follow a special diet
- speech and language therapy advice on eating and swallowing
- dietitian input
- regular support worker or Personal Assistant support

Common mistake: a real-life example

Many families underestimate the amount of support they provide, because it has become part of everyday life.

Priya

Priya is 20 and lives at home.
Her family initially said: "She can make her own meals" and "She makes her own lunch."

Further discussion revealed that:

- Dad does all the food shopping.
- Mum decides what lunch will be and leaves it out for her.
- Mum checks afterwards that Priya has actually eaten it.
- Priya only makes toast or cereal unless someone helps.
- She often forgets to drink unless reminded.
- She would eat crisps for every meal if given the choice.
- Mum checks that her gluten-free diet is followed.

The assessment recognised that although Priya could prepare simple food, she needed considerable support to manage her nutrition safely and healthily.

Being able to make a sandwich or heat a ready meal does not mean someone can manage their nutrition.

The assessment should also consider:

- planning meals across the week
- shopping and budgeting for food
- storing food safely
- eating a reasonably balanced diet
- eating and drinking regularly without reminders
- doing all of this consistently, every day

Future planning prompt

Consider: if my son or daughter lived independently tomorrow, what would they eat this week?

Think about:

- who would plan the meals
- who would do the shopping
- what they could cook safely
- whether they would remember to eat and drink
- whether their diet would be healthy
- any special dietary or swallowing needs

Outcome 2: Maintaining personal hygiene



What does this mean?

The Care Act considers whether a person can keep themselves clean, both their body and their clothes, to a reasonable standard.

This is much broader than simply "having a shower". It includes the ability to:

- Wash, bathe or shower regularly.
- Wash and dry their hair.
- Clean their teeth thoroughly, at least twice a day.
- Shave, or manage other hair removal if they wish.
- Manage periods, if applicable.
- Use deodorant.
- Cut or file nails, or arrange for this to be done.
- Wash their hands, especially after using the toilet and before eating.
- Recognise when they need to wash.
- Look after their skin, including applying creams if needed.

The assessment should consider both practical skills and the ability to carry them out consistently.

Why does it matter?

Many people can wash when directed or supervised, but may struggle to:

- recognise when they need a wash or a change
- remember to wash or clean their teeth
- wash thoroughly, rather than quickly
- set a safe water temperature
- keep to a regular routine

Good hygiene matters for health, dignity and relationships. Poor hygiene can lead to skin problems, infections and dental disease, and can affect how other people respond to someone at college, at work or socially. Some people with Down syndrome have dry or sensitive skin, gum disease or reduced fine motor skills, which can make hygiene tasks harder.

Questions to consider

Washing and bathing

Can they:
get in and out of the bath or shower safely?
set a safe water temperature?
wash all of their body thoroughly?

- wash and rinse their hair properly?
- dry themselves properly?

Do they:
- need prompting to wash?
- need someone to check they have washed thoroughly?
- avoid washing unless reminded?
- take a very long time?

Teeth and oral care

Can they:
- brush their teeth thoroughly?
- brush for long enough?
- remember to brush twice a day?
- recognise and report tooth pain?

Grooming

Can they:
- shave safely?
- cut or file their nails?
- brush or style their hair?
- use deodorant?
- apply creams or lotions?

Periods (if applicable)

Can they:
- recognise when a period has started?
- use and change sanitary products?
- dispose of products hygienically?
- keep track of their cycle?

Hand washing

Do they:
- wash their hands after using the toilet?
- wash their hands before eating or preparing food?
- wash thoroughly with soap?

What support might be needed?

Support may include:
- prompting and reminders
- supervision
- hands-on help with some tasks
- visual routines in the bathroom
- timers for teeth brushing

- thermostatic valves to control water temperature
- aids and adaptations, such as grab rails or a shower seat
- occupational therapy assessment
- regular support worker or Personal Assistant support

Common mistake: a real-life example

Many families underestimate the amount of support they provide, because it has become part of everyday life.

Sophie

Sophie is 24 and attends a local college.
Her family initially said: "She's fine with washing" and "She showers herself."

Further discussion revealed that:

- Mum tells Sophie when it is shower night.
- Mum runs the shower, checks the water temperature and reminds her to use shampoo.
- Sophie often leaves shampoo or conditioner in her hair, so Mum checks it has been rinsed out.
- Mum reminds her to brush her teeth every morning and evening.
- Mum helps her manage her periods.
- Mum cuts her nails.

The assessment recognised that although Sophie could wash herself, she needed regular prompting, checking and practical help to maintain her personal hygiene.
Being able to get into the shower does not mean someone can manage their personal hygiene.

The assessment should also consider:

- recognising when a wash is needed
- remembering to wash without reminders
- washing thoroughly and safely
- caring for teeth, hair, nails and skin
- doing all of this consistently

Future planning prompt

Consider: if my son or daughter lived independently tomorrow, would they stay clean and well-groomed without anyone reminding them?

Think about:

- washing (including hands) and showering
- teeth
- hair
- shaving and nails
- periods

Outcome 3: Managing toilet needs



What does this mean?

The Care Act considers whether a person can access and use a toilet, and manage their toilet needs, safely and hygienically.

This is broader than simply "being toilet trained". It includes the ability to:

- Recognise the need to use the toilet in good time.
- Get to the toilet and use it safely.
- Wipe themselves thoroughly.
- Flush the toilet.
- Adjust clothing before and after.
- Wash their hands afterwards.
- Manage any continence products, if used.
- Deal with accidents, including changing clothes and cleaning up.
- Use unfamiliar or public toilets.
- Recognise and report changes, such as constipation, pain or blood.

The assessment should consider both practical skills and the ability to carry them out consistently.

Why does it matter?

Many people can use the toilet independently most of the time, but may struggle to:

- wipe thoroughly without help or checking
- recognise and respond to the need in time
- manage when they are unwell, for example with diarrhoea
- cope with unfamiliar toilets when out and about
- tell someone when something is wrong

This is an area families often find hard to talk about, and the support they give may be quietly overlooked. People with Down syndrome may be more likely to experience constipation, urinary infections or, later in life, continence changes linked to dementia. Toilet needs affect dignity, health, skin integrity and confidence to go out.

Questions to consider

Using the toilet

Can they:

- recognise when they need to go?
- get to the toilet in time?
- manage their clothing?
- wipe themselves thoroughly?
- flush and wash their hands?

Do they:

- need reminders to go to the toilet?
- need someone to check they have wiped properly?
- have accidents, including at night?
- take a long time?

Out and about

Can they:

- find and use public toilets?
- use unfamiliar toilets, such as at college, work or friends' homes?
- manage accessible or radar key toilets?
- ask for help if needed?

Accidents and continence

Can they:

- recognise when they have had an accident?
- change their clothes and clean themselves?
- deal with soiled clothing and bedding?
- use and dispose of continence products?

Health

Do they:

- recognise and report constipation, pain or changes?
- understand the need to drink enough fluids?
- need support with medication for bowel or bladder conditions?

What support might be needed?

Support may include:

- prompting and reminders, including before going out
- checking, and help with wiping or cleaning up
- a visual toilet and handwashing routine
- help to find and use public and accessible toilets (including a RADAR key)
- continence assessment and products, through the GP or continence service
- support to manage constipation, including diet, fluids and medication
- aids and adaptations, such as grab rails or a raised toilet seat
- occupational therapy assessment
- regular support worker or Personal Assistant support

Common mistake: a real-life example

Many families underestimate the amount of support they provide, because it has become part of everyday life.

Kwame

Kwame is 19 and has just finished school. His family initially said: "He has no problems with the toilet" and "He's fully toilet trained."

Further discussion revealed that:

- Mum reminds Kwame to go before leaving the house.
- Kwame does not wipe thoroughly, so Mum checks his underwear and changes it.
- He needs reminding to wash his hands afterwards.
- He avoids public toilets and has had accidents when out.
- When he is unwell, Mum helps him clean up after accidents.
- He has frequent constipation, which he does not mention unless asked.
- Mum deals with any soiled bedding.

The assessment recognised that Kwame needed regular prompting, checking and practical help to manage his toilet needs, especially away from home.
Being able to use the toilet at home does not mean someone can manage their toilet needs.

The assessment should also consider:

- recognising the need in time
- wiping and hand washing thoroughly
- using unfamiliar and public toilets
- managing accidents
- noticing and reporting health changes
- doing all of this consistently, including when unwell

Future planning prompt

Consider: if my son or daughter lived independently tomorrow, would anyone know if they were struggling with their toilet needs?

Think about:

- wiping and hygiene
- accidents
- night-time
- public toilets
- constipation and health changes
- continence products

Outcome 4: Being appropriately clothed



What does this mean?

The Care Act considers whether a person can dress themselves, and be appropriately dressed for the weather and for what they are doing.

This is much broader than simply "getting dressed". It includes the ability to:

- Choose suitable clothes for the weather and the activity.
- Put clothes on and take them off.
- Manage fastenings such as buttons, zips, laces and bras.
- Put clothes on the right way round and in the right order.
- Recognise when clothes are dirty, damaged or no longer fit.
- Change into clean clothes regularly.
- Dress appropriately for the setting, such as work, college or a job interview.
- Change into nightwear and back again.
- Buy or replace clothes and shoes when needed.
- Manage footwear, including putting on shoes and socks.

The assessment should consider both practical skills and the ability to carry them out consistently.

Why does it matter?

Many people can dress themselves when clothes are laid out for them, but may struggle to:

- choose clothes that suit the weather, such as a coat in winter
- recognise when clothes need changing
- notice clothes that are inside out, back to front or stained
- manage fiddly fastenings
- dress appropriately for different situations

Being appropriately clothed affects health, comfort, safety and dignity. It also affects how other people respond, for example at work or college. Some people with Down syndrome have reduced fine motor skills, low muscle tone or sensory preferences that make some clothes harder to manage.

Questions to consider

Choosing clothes

Can they:

- choose clothes suitable for the weather?
- choose clothes suitable for the activity, such as work, sport or a party?
- choose clean clothes?
- match clothes in a way they are happy with?

Do they:

- need clothes laid out for them?
- wear the same clothes repeatedly unless prompted?
- insist on unsuitable clothes, such as shorts in the snow?

Getting dressed and undressed

Can they:

- put on and take off all their clothes?
- manage buttons, zips and bras?
- tie laces or manage other fastenings?
- put clothes on the right way round?
- put on socks, tights and shoes?

Do they:

- need help with some items?
- need someone to check how they look before going out?
- take a very long time?

Looking after clothes

Can they:

- recognise when clothes are dirty or need washing?
- notice when clothes are damaged or no longer fit?
- buy new clothes or shoes when needed?

What support might be needed?

Support may include:

- prompting and reminders
- laying out clothes, or a simplified wardrobe
- visual guides showing what to wear in different weather
- checking appearance before going out
- help with fastenings
- adapted clothing, such as Velcro shoes or elasticated waists
- support with clothes shopping
- regular support worker or Personal Assistant support

Common mistake: a real-life example

Many families underestimate the amount of support they provide, because it has become part of everyday life.

Daniel

Daniel is 22 and works two mornings a week in a café.
His family initially said: "He gets himself dressed."

Further discussion revealed that:

- Mum chooses his clothes and lays them out the night before.
- Daniel would wear his favourite football shirt every day if allowed.
- He cannot tie his laces, so he wears slip-on shoes.
- He often goes out without a coat, even in the rain.
- Mum checks how he looks before he leaves the house, including that his work uniform is clean and on correctly.

The assessment recognised that although Daniel could physically dress himself, he needed daily prompting and checking to be appropriately clothed.
Being able to put clothes on does not mean someone can be appropriately clothed.

The assessment should also consider:

- choosing clothes suitable for the weather and setting
- recognising when clothes need changing
- managing fastenings and footwear
- checking their appearance
- doing all of this consistently, every day

Future planning prompt

Consider: if my son or daughter lived independently tomorrow, would they be dressed suitably for the day ahead?

Think about:

- weather
- work, college or social events
- clean clothes
- fastenings and footwear
- buying new clothes
- nightwear and changing

Outcome 5: Being able to make use of the home safely



What does this mean?

The Care Act considers whether a person can move around their home safely and use the rooms and facilities in it, including getting in and out of the property.
This is broader than simply "getting around the house".

It includes the ability to:

- Move safely between rooms and use the stairs.
- Get in and out of bed, chairs, the bath or shower.
- Use the kitchen and bathroom safely.
- Lock and unlock doors, and keep keys safe.
- Answer the door safely and decide who to let in.
- Recognise and avoid hazards, such as trip hazards or hot surfaces.
- Respond to emergencies, such as a fire alarm, flood or power cut.
- Know how and when to call for help.
- Use heating, lighting and hot water safely.
- Stay safe at home when alone, including at night.

The assessment should consider both practical skills and the ability to carry them out consistently.

Why does it matter?

Many people can move around their home without difficulty, but may struggle to:

- recognise danger, such as a pan left on the hob
- respond quickly and appropriately in an emergency
- judge who is safe to let into the home
- remember to lock the door at night
- stay safe when nobody else is there

People with Down syndrome are often trusting and friendly, which can make them vulnerable to cold callers, scams or people taking advantage of them. Reduced depth perception, hearing loss or low muscle tone can also increase the risk of falls or of not noticing alarms.

Questions to consider

Moving around

Can they:

- use the stairs safely?
- get in and out of bed, chairs, the bath and shower?
- move around without tripping or falling?
- see well enough in low light, such as at night?

Security

Can they:
- lock and unlock doors and windows?
- keep track of their keys?
- remember to lock up at night or when going out?

Do they:
- open the door to anyone?
- understand who is safe to let in?
- recognise scams, cold callers or suspicious phone calls?

Emergencies

Can they:
- recognise a fire alarm or smoke alarm and know what to do?
- leave the property safely in an emergency?
- call 999 and explain what has happened?
- contact a family member or support worker for help?
- cope with a power cut, flood or a locked-out situation?

Being home alone

Can they:
- stay safely at home alone for a few hours?
- stay overnight alone?
- cope if something unexpected happens?

Do they:
- become anxious when alone?
- need regular check-ins by phone?

What support might be needed?

Support may include:
- safety training and practice, such as fire drills
- visual safety reminders
- a key safe or keyless door lock
- a video doorbell
- assistive technology, such as telecare alarms, sensors or a pendant alarm
- adapted alarms for people with hearing loss
- grab rails, stair rails or better lighting
- regular phone or video check-ins
- occupational therapy assessment
- regular support worker or Personal Assistant support

Common mistake: a real-life example

Many families underestimate the amount of support they provide, because it has become part of everyday life.

Mei

Mei is 26 and would like to live in her own flat one day.
Her family initially said: "She's safe at home" and "She's fine on her own."

Further discussion revealed that:

- Mei is only ever left alone for an hour or so, with a neighbour on standby and a phone call halfway through.
- She has never been left alone overnight.
- She once let a stranger in because he said he was from "the council".
- She did not respond when the smoke alarm went off during cooking.
- She has mild hearing loss and does not always hear the doorbell or alarms.
- Mum checks the doors are locked every night.

The assessment recognised that Mei needed support, training and assistive technology to make use of her home safely.
Being able to move around the home does not mean someone can make use of it safely.

The assessment should also consider:

- recognising and responding to hazards
- keeping the home secure
- deciding who to let in
- coping with emergencies
- getting help when needed
- staying safe consistently, including at night

Future planning prompt

Consider: if my son or daughter lived independently tomorrow, what would happen if something went wrong at 2am?

Think about:

- fire and smoke alarms
- locking up
- visitors and cold callers
- falls
- calling for help
- being alone at night

Outcome 6: Maintaining a habitable home environment



What does this mean?

The Care Act considers whether a person can maintain a home environment that is safe, hygienic and suitable to live in. This is much broader than simply "doing housework".

It includes the ability to:

- Keep living spaces reasonably clean and safe.
- Keep kitchens and bathrooms hygienic.
- Manage laundry.
- Change bedding.
- Dispose of rubbish appropriately.
- Recognise when cleaning is needed.
- Organise and store belongings.
- Identify and report maintenance issues.
- Use household appliances safely.
- Contribute to household tasks where appropriate.

The Care Act guidance also recognises that keeping a home habitable can include managing the essentials that keep it running, such as paying rent and bills so that gas, electricity and water stay connected.

The assessment should consider both practical skills and the ability to carry them out consistently.

Why does it matter?

Many people can complete household tasks when directed or supervised, but may struggle to:

- recognise when a task needs doing
- remember to do it
- plan the order of tasks
- complete tasks safely
- maintain standards consistently

These difficulties can significantly affect someone's ability to live independently.

Questions to consider

Cleaning and household management

Can they:

- vacuum or sweep floors?
- clean kitchen surfaces?
- clean bathrooms?
- wash dishes?
- recognise when cleaning is needed?

Do they:
- need prompting?
- require supervision?
- avoid tasks unless someone reminds them?

Laundry

Can they:
- recognise dirty clothing?
- separate laundry?
- use a washing machine?
- use a tumble dryer safely?
- put clothes away afterwards?

Bedroom and personal space

Can they:
- keep their room reasonably tidy?
- change bedding?
- organise belongings?
- find important items when needed?

Household appliances

Can they safely use:
- washing machines?
- ovens?
- hobs?
- kettles?
- microwaves?

Do they:
- understand safety risks?
- need supervision?
- remember to switch appliances off?

Maintenance and safety

Can they:
- identify hazards?
- report problems?
- understand when repairs are needed?
- respond appropriately if something goes wrong?

Examples might include:
- broken appliances
- water leaks
- electrical faults
- smoke alarm activation

Rent, bills and utilities

Can they:

- understand that rent and bills must be paid?
- keep track of when payments are due?
- top up a prepayment meter, if they have one?
- recognise when a letter needs action?

What support might be needed?

Support may include:

- prompting
- supervision
- practical assistance
- household routines
- visual schedules
- supported practice
- help to manage bills and post
- regular support worker input
- Personal Assistant support

Common mistake: a real-life example

Many families underestimate the amount of support they provide, because it has become part of everyday life.

Oliver

Oliver hopes to move into supported living in the future.
During assessment, his family initially said: "He can do washing" and "I only remind him to do it."

Further discussion revealed that:

- Mum sorts all his clothing.
- Mum reminds him every time.
- Mum checksdetergent.
- Mum moves clothes to the dryer.
- Mum reminds him to put clothes away.

The assessment recognised that although Oliver could complete parts of the task, he still required considerable support to manage laundry independently.
Even "only reminding" counts: if reminders are required every week, that is support. Likewise, if you say "she can cook", the assessor may need to understand what meals, how often, how much supervision, and what happens if nobody reminds her.

Using the washing machine is only one part of maintaining a habitable home.
The assessment should also consider:

- recognising laundry needs doing
- organising clothes
- remembering the task
- completing it safely
- putting clothes away afterwards
- doing this consistently

Future planning prompt

Consider: if my son or daughter lived independently tomorrow, what household tasks would still require support?

Think about:

- cooking
- shopping
- laundry
- cleaning
- organising belongings
- safety
- maintenance

This can provide a useful starting point for identifying support needs and future goals.

Outcome 7: Developing and maintaining family or other personal relationships



What does this mean?

The Care Act considers whether a person is able to develop and keep up relationships with family, friends and others, and whether they are lonely or isolated as a result of their needs.

This is much broader than simply "having a family". It includes the ability to:

- Stay in touch with family members, including those who live elsewhere.
- Make new friends and keep existing friendships going.
- Arrange to meet up with people.
- Use the phone, messaging, video calls and social media.
- Remember birthdays and important events.
- Develop romantic and intimate relationships, if they wish.
- Understand healthy relationships, consent and personal boundaries.
- Recognise when a relationship is unhealthy, exploitative or unsafe.
- Resolve disagreements and cope with conflict.
- Take part in social occasions and groups.

The assessment should consider both practical skills and the ability to carry them out consistently.

Why does it matter?

Many people enjoy being with others and are warm and sociable, but may struggle to:

- arrange to see friends without someone else organising it
- travel to meet people
- keep friendships going once school or college ends
- understand when someone is not a real friend
- stay safe online and in person

Loneliness is a real risk for many young adults with Down syndrome after leaving education, when daily contact with friends can suddenly stop. Friendly, trusting natures can also make some people vulnerable to exploitation, including "mate crime" and online grooming. Relationships matter enormously for emotional wellbeing, confidence and mental health.

Questions to consider

Family

Can they:

- keep in touch with relatives who do not live with them?
- arrange visits or calls?
- remember important family dates?

Friendships

Can they:
- make new friends?
- arrange to meet friends?
- get to where they are meeting?
- keep friendships going over time?

Do they:
- rely on parents to organise all social contact?
- see friends only at organised groups?
- feel lonely or isolated?

Communication and technology

Can they:
- use a phone to call or message people?
- use video calls or social media?
- understand what is safe to share online?
- recognise suspicious messages or requests?

Intimate relationships

Do they:
- wish to have a boyfriend, girlfriend or partner?
- understand consent, privacy and personal boundaries?
- know about sexual health and contraception?
- recognise when a relationship is unhealthy or unsafe?

Staying safe

Can they:
- recognise when someone is taking advantage of them, for example borrowing money?
- say no and tell someone if they are worried?
- tell the difference between friends, acquaintances and strangers?

What support might be needed?

Support may include:
- help to arrange and plan social activities
- support to travel to see friends and family
- support to use phones, video calls and social media safely
- friendship and social groups
- relationships and sex education in an accessible format
- support to understand consent and boundaries
- befriending services
- regular support worker or Personal Assistant support

Common mistake: a real-life example

Many families underestimate the amount of support they provide, because it has become part of everyday life.

Marcus

Marcus is 21 and left college last summer.
His family initially said: "He's very sociable, everyone loves him" and "He has lots of friends."

Further discussion revealed that:

- Since leaving college, Marcus rarely sees his friends.
- Mum arranges every meet-up by messaging other parents.
- Marcus cannot travel to friends' houses alone, so Mum drives him.
- He has given money to someone he met online who said they were his girlfriend.
- He has become low and withdrawn at weekends.

The assessment recognised that Marcus needed support to maintain friendships, stay safe in relationships, and reduce his isolation.
Being sociable and friendly does not mean someone can develop and maintain relationships.

The assessment should also consider:

- arranging contact independently
- getting to see people
- keeping relationships going over time
- understanding healthy relationships and boundaries
- staying safe in person and online
- whether they feel lonely or isolated

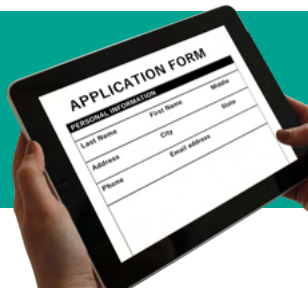
Future planning prompt

Consider: if my son or daughter lived independently tomorrow, who would they see each week, and how would that happen?

Think about:

- family contact
- friendships
- romantic relationships
- travel to see people
- online safety
- loneliness

Outcome 8: Accessing and engaging in work, training, education or volunteering



What does this mean?

The Care Act considers whether a person has the opportunity, and is able, to take part in work, training, education or volunteering, if they wish to.

This is much broader than simply "going to college". It includes the ability to:

- Find out about and choose suitable opportunities.
- Apply for courses, jobs or volunteering roles, and attend interviews.
- Get to and from the place of work or study.
- Arrive on time and keep to a timetable.
- Understand and follow instructions.
- Manage the social side of work or college, such as breaks and teamwork.
- Cope with changes to routine or unexpected situations.
- Manage workplace expectations, such as appropriate behaviour and dress.
- Ask for help when needed.
- Keep going over time, not just for a short placement.

The assessment should consider both practical skills and the ability to carry them out consistently.

Why does it matter?

Many people are keen and capable workers or learners, but may struggle to:

- find opportunities and complete applications
- travel independently to work or college
- understand verbal instructions given quickly
- cope with a change of task, staff or routine
- manage the social expectations of a workplace

Work, learning and volunteering give purpose, structure, friendships, income and self-esteem. Many young people with Down syndrome face a "cliff edge" when school or college ends, with fewer structured opportunities available. If an Education, Health and Care Plan (EHCP) is in place, think about how Care Act support will link with it, and what will happen when education ends.

Questions to consider

Finding opportunities

Can they:

- find out about courses, jobs or volunteering?
- complete application forms?
- attend and manage an interview?
- make choices about what they want to do?

Getting there

Can they:

- travel to work or college independently?
- arrive on time?
- cope if transport is delayed or cancelled?

Doing the work or learning

Can they:

- understand and follow instructions?
- stay focused on a task?
- work alongside others?
- ask for help when stuck?
- manage breaks and lunchtimes?

Do they:

- need a job coach or learning support?
- need tasks broken down into steps?
- become anxious with changes to routine?
- need visual or written instructions?

Workplace skills

Can they:

- understand workplace rules and expectations?
- manage their wages or any benefits?
- deal with problems or conflict at work?
- recognise if they are being treated unfairly?

What support might be needed?

Support may include:

- help to find suitable opportunities
- supported internships or supported employment programmes
- job coaching
- travel training
- support with applications and interviews
- visual task lists and routines
- workplace adjustments
- Access to Work funding
- regular support worker or Personal Assistant support

Common mistake: a real-life example

Many families underestimate the amount of support they provide, because it has become part of everyday life.

Ellie

Ellie is 23 and wants to work in a nursery.
Her family initially said: "She goes to her volunteering at a charity shop every Tuesday."

Further discussion revealed that:

- Mum found the placement and spoke to the manager.
- Mum drives Grace there and collects her.
- Mum reminds her what to take and sorts out any problems with the manager.
- A staff member gives Grace one task at a time and checks her work.
- Grace becomes upset if her usual tasks change.
- She has never completed a job application on her own.

The assessment recognised that Grace needed support to find opportunities, travel, and manage tasks in order to work towards paid employment.
Attending a placement does not mean someone can access and engage in work or education independently.

The assessment should also consider:

- finding and applying for opportunities
- travelling there and back
- understanding instructions and expectations
- managing changes and problems
- the support already in place from staff or job coaches
- keeping it going over time

Future planning prompt

Consider: if my son or daughter lived independently tomorrow, how would they spend their weekdays?

Think about:

- work or volunteering
- college or training
- travel
- applications and interviews
- coping with change
- long-term goals

Outcome 9: Making use of necessary facilities or services in the local community



What does this mean?

The Care Act considers whether a person can get around their local community safely and use the facilities and services they need, including public transport and recreational facilities.

This is much broader than simply "going out". It includes the ability to:

- Use public transport, such as buses and trains, or arrange other transport.
- Plan a journey and cope with delays or changes.
- Cross roads and stay safe near traffic.
- Use shops, banks, post offices and cafés.
- Handle money and pay for things.
- Attend GP, dental, hospital and other health appointments.
- Use leisure facilities, such as gyms, swimming pools, cinemas and libraries.
- Take part in clubs, groups, faith communities and hobbies.
- Ask for help or directions if lost.
- Recognise and avoid unsafe situations or people.

The assessment should consider both practical skills and the ability to carry them out consistently.

Why does it matter?

Many people can make familiar journeys or use local shops with practice, but may struggle to:

- cope when a bus is cancelled or a route changes
- manage money and check change
- know what to do if they get lost
- explain their needs to staff, such as at a GP surgery
- recognise strangers who may take advantage

Being part of the community supports independence, health, friendships and a sense of belonging. Without support, some people become confined to home or rely entirely on family to get anywhere.

Questions to consider

Travel and transport

Can they:

- use buses or trains independently?
- plan a journey, including new routes?
- cope with delays, cancellations or diversions?
- cross roads safely?
- know what to do if they get lost?

Do they:

- only manage familiar, practised routes?
- need someone with them?
- rely on lifts from family?
- have a bus pass or Disabled Persons Railcard?

Shops and services

Can they:

- go into a shop and buy what they need?
- pay and check their change?
- use a bank card safely and keep their PIN private?
- use a cash machine?
- ask staff for help?

Health appointments

Can they:

- book an appointment?
- get to the appointment?
- explain their symptoms?
- understand and remember what they are told?
- collect prescriptions?

Leisure and recreation

Can they:

- find out what activities are available?
- get to clubs, classes or groups?
- take part without support?

Safety in the community

Can they:

- recognise unsafe people or situations?
- keep their money and phone safe?
- call for help if something goes wrong?

What support might be needed?

Support may include:

- travel training
- a companion bus pass or Disabled Persons Railcard
- journey planning apps or visual route guides
- support to handle money
- support at health appointments
- a hospital passport
- support to join and attend clubs or activities
- a personal safety plan, or a local safe places scheme
- regular support worker or Personal Assistant support

Common mistake: a real-life example

Many families underestimate the amount of support they provide, because it has become part of everyday life.

Aisha

Aisha is 25 and enjoys swimming and going to the cinema.
Her family initially said: "She's very independent in the community."

Further discussion revealed that:

- Aisha can walk to her local shop but does not use public transport alone.
- She hands over her purse to shop staff when paying.
- Mum books and attends all her health appointments.
- She only goes swimming when her sister takes her.
- She became very distressed when she got lost in town last year.

The assessment recognised that Aisha needed support with travel, money and appointments to make use of her community safely.

Even where someone does travel alone, look closely. "He gets the bus to college on his own" may mean one practised route, with Mum tracking his phone and a call home if the bus does not come. That is still support.

Managing one familiar journey does not mean someone can make use of their community.

The assessment should also consider:

- new or unfamiliar journeys
- coping with delays and changes
- handling money
- using health services
- taking part in leisure activities
- staying safe consistently

Future planning prompt

Consider: if my son or daughter lived independently tomorrow, where could they get to on their own, and where would they need help?

Think about:

- buses and trains
- shops and money
- health appointments
- leisure and hobbies
- getting lost
- staying safe

Outcome 10: Carrying out any caring responsibilities for a child



What does this mean?

The Care Act considers whether a person who has parenting or caring responsibilities for a child is able to carry them out.

This outcome only applies if your son or daughter is a parent, or has caring responsibilities for a child, such as a step-child or a younger relative they look after. For many families it will not apply, but it is still worth reading, because some adults with Down syndrome do become parents and it is important that support is planned early.

Where it applies, it includes the ability to:

- Meet the child's daily needs, such as feeding, washing, dressing and changing.
- Keep the child safe at home and when out.
- Recognise when the child is unwell and seek medical help.
- Take the child to appointments, nursery or school.
- Understand and respond to the child's changing needs as they grow.
- Provide routines, boundaries and emotional warmth.
- Manage money and the household to meet the child's needs.
- Work with health visitors, schools and other professionals.

The assessment should consider both practical skills and the ability to carry them out consistently.

Why does it matter?

Parents with a learning disability have the same right to family life as anyone else. With the right support, many can parent successfully. Without it, they can struggle to:

- keep up with a baby's or child's changing needs
- recognise risks and danger
- understand professional advice
- manage appointments and paperwork
- cope with the demands of parenting alongside their own needs

Good, early support can help keep families together. It is important that any assessment looks at what support would make parenting possible, rather than only at what the parent finds difficult.

Questions to consider

Daily care

Can they:

- feed, wash, dress and change the child?
- follow routines for sleep and meals?
- recognise when the child is hungry, tired or upset?

Safety and health

Can they:

- keep the child safe from hazards at home?
- recognise when the child is unwell?
- give medicine correctly?
- call for help in an emergency?

Appointments and education

Can they:

- attend health visitor, GP and other appointments?
- get the child to nursery or school on time?
- understand letters and information from professionals?

Support around them

Do they:

- have a partner or family members who help?
- know who to ask for advice?
- have access to parenting support in an accessible format?

What support might be needed?

Support may include:

- parenting support adapted for people with a learning disability
- easy-read parenting information
- visual routines and reminders
- support at appointments
- help with household management linked to the child's needs
- support from a learning disability nurse or health visitor
- an advocate
- regular support worker or Personal Assistant support

Common mistake: a real-life example

Families and grandparents often step in quietly and do a great deal of the caring.

Kasia

Kasia is 29 and has a two-year-old son.
Her family initially said: "She's a lovely mum and manages really well with him."

That is absolutely true, but further discussion revealed that:

- Kasia's mum visits every day to help with meals and bath time.
- Her mum makes up the bottles and sometimes stays overnight to help.
- Kasia finds it hard to understand the health visitor's advice.
- Her mum keeps track of vaccinations and sorts out appointments.
- Kasia was unsure what to do when her son had a high temperature.

The assessment recognised that Kasia was a loving parent who needed regular, practical support to carry out her caring responsibilities.

Loving and caring for a child well in some areas does not mean a parent needs no support.

The assessment should also consider:

- meeting all of the child's daily needs
- keeping the child safe
- recognising illness
- managing appointments and professionals
- the support family already provide
- doing all of this consistently as the child grows

Future planning prompt

Consider: if my son or daughter became a parent, or took on caring for a child, what support would they need to do this well?

Think about:

- daily care
- safety
- health and illness
- appointments
- support from family
- accessible parenting advice

Preparing for the assessment

Good preparation is the best way to make sure the assessment reflects your son or daughter's real life and the support they need.

Before the assessment

- Keep a diary for one or two weeks. Note every time you prompt, remind, check, help or step in. Families are often surprised by how much they do.
- Gather real examples. Specific examples, such as "Last Tuesday he left the hob on", carry more weight than general statements.
- Think about bad days, not just good days. Include times when they are tired, unwell, anxious, or when routines change.
- Collect reports. Letters from the GP, specialists, speech and language therapy, occupational therapy, school or college, and any EHCP can all help.
- Prepare your son or daughter. Explain what the assessment is for, in a way they understand. Talk about their hopes, wishes and goals.
- Ask for reasonable adjustments. For example, a familiar setting, extra time, easy-read information, breaks, or a trusted person present.

During the assessment

- Remember that your son or daughter may say "yes, I can do that" because they want to please or want to appear capable. Gently add context afterwards, ideally in a way that protects their dignity.
- Explain what happens without your support, not only what happens with it.
- Use the four tests: can they do it without help, safely, without distress, and in a reasonable time?
- Mention any health conditions that affect them, and whether their abilities vary.

After the assessment

- Ask for a written copy of the assessment.
- Check it carefully. If anything is missing or wrong, put your comments in writing.
- If you disagree with the outcome, you can ask the local authority to review it, and use its complaints procedure if needed and, if it’s still not resolved, the Local Government and Social Care Ombudsman.

Transition assessments for young people

Your son or daughter does not have to wait until they turn 18. A local authority must carry out a transition assessment for a young person under 18 if they are likely to have needs for care and support after turning 18, and the assessment would be of "significant benefit" — usually when the timing helps plan for adulthood. Ask early, ideally from around age 14 alongside any EHCP preparing for adulthood reviews.

Your own needs as a carer

As a parent carer, you are entitled to a carer's assessment in your own right. This looks at the impact caring has on your own wellbeing, work, health and life, and whether you are willing and able to keep providing the same level of care. Your needs should be considered separately from your son or daughter's. Remember: the support you choose to give should not be used as a reason to overlook your son or daughter's needs. The assessment should identify all their needs first, and then consider what you are willing and able to continue providing.

Independent advocacy

If your son or daughter would have substantial difficulty taking part in the assessment, and there is no appropriate person to support them, the local authority must arrange an independent advocate. Even where you are supporting them, you can ask whether an advocate would help them express their own views.

Mental capacity

Adults are presumed to have capacity to make their own decisions unless it is shown otherwise. If there are doubts about a particular decision, the Mental Capacity Act 2005 sets out how capacity should be assessed and how decisions should be made in the person's best interests. Your son or daughter should be supported to make as many decisions as possible for themselves.

Summary checklist

- [ ] I have worked through all ten outcomes and noted examples for each.
- [ ] I have kept a diary of the support I provide.
- [ ] I have recorded what happens on bad days and when routines change.
- [ ] I have gathered relevant reports and letters.
- [ ] My son or daughter knows what the assessment is for and has shared their own views and goals.
- [ ] I have asked for any reasonable adjustments.
- [ ] I have asked about a carer's assessment for myself.
- [ ] I have considered whether an independent advocate is needed.
- [ ] I know to ask for a written copy of the assessment and to check it carefully.