DSUK
Down Syndrome UK

Future Pathways

Part 1: Understanding Adult Social Care



Introduction

Many families describe adult social care as one of the most confusing parts of adult life. The terminology can feel overwhelming, the processes are unfamiliar, and support may look very different from the services your family experienced in childhood.

At its heart, adult social care is about helping people achieve the outcomes that matter to them and supporting their wellbeing. While support may include help with personal care and daily living, it can also support work, volunteering, friendships, community life, housing and independence.

A key shift between children's and adult services is that adult social care focuses on the individual: their aspirations and the outcomes they want to achieve.

Understanding how the system works helps you feel more confident, better prepared and better able to speak up for the right support.



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.

Key terms

Term	Plain English meaning
Local authority	Your county, city or borough council. It is responsible for adult social care (sometimes called "the council" or "social services").
Care Act 2014	The law that sets out what councils must do in England.
Needs assessment	A conversation (or series of them) about how the person's disability affects daily life and what support would help.
Outcomes	The ten everyday areas of life the law asks councils to consider (see below).
Eligible needs	Needs that meet the national test, which means the council has a duty to meet them.
Care and Support Plan	A written plan setting out eligible needs, goals and how they will be met.
Personal budget	The amount of money the council calculates is needed to meet eligible needs. (Part 2)
Advocate	An independent person who helps someone to be heard and take part in decisions.
Transition	The move from children's services to adult services.

The key laws

Law	What it covers	Ages
Care Act 2014	Adult social care: assessments, eligibility, care plans, charging, carers	18+, and transition assessments before 18
Mental Capacity Act 2005	Decision-making, capacity and best interests	16+
Children and Families Act 2014 (SEND Code of Practice)	EHCPs and preparing for adulthood	0 to 25
Children Act 1989	Children's social care and safeguarding	Under 18
Chronically Sick and Disabled Persons Act 1970	Services for disabled children, such as adaptations, leisure and travel	Under 18 in England (adults' services were replaced by the Care Act in 2015)

Useful guidance, all on GOV.UK: the Care and Support Statutory Guidance, the Mental Capacity Act Code of Practice, and the SEND Code of Practice.

A note about how this feels

An assessment can feel like a long list of everything your family member cannot do. That can be upsetting, especially when you are proud of how much they have achieved. It helps to remember two things:

- Describing difficulties honestly is not negative. It is how the council understands what support is needed. Under-describing needs is a bigger risk than over-describing them.
- A good assessment also records strengths, aspirations and what the person wants from life. You can, and should, talk about both.

The four stages of adult social care: a simplified view

Most people experience adult social care in four broad stages. This is a simplified way of looking at the process. It is not exactly how the Care Act is structured, and in real life the stages can overlap, repeat or happen in a different order. For young people, preparation begins earlier through transition (see below).

Stage	What happens
1. Needs assessment	The council looks at needs, strengths, aspirations and outcomes.
2. Eligibility	The council decides whether needs meet the national eligibility criteria.
3. Care and Support Plan	Eligible needs are turned into a plan for meeting them.
4. Financial assessment	The council considers whether the person must contribute towards the cost.

Eligibility is never decided by finances. The council decides what needs are eligible first. Whether the person pays anything towards support is considered separately, afterwards.

Growing up: transition from children's to adult services

For young people with Down syndrome, adult social care does not start at 18. Planning should begin much earlier.

Transition assessments

If a young person is likely to have care and support needs once they turn 18, the council **must** carry out a **transition assessment** when it would be of significant benefit to them. A young person does not need to be receiving social care now to be assessed. **There is no set age**. Ask from Year 9 (age 13 - 14): many councils don't start until 16 or 17 unless you ask, so don't wait to be offered one. If you ask for a transition assessment and the council refuses, it must give you its reasons in writing.

A transition assessment looks at:

- the young person's likely needs and goals as an adult
- what outcomes matter to them (education, work, friends, where to live)
- whether they are likely to have eligible needs at 18
- what the family currently provides, and what would happen as parents age

The assessment should be **completed in time for the young person to move smoothly into adult services**. If your young person is getting children's social care support and turns 18 before the council has finished, that support must carry on until adult support starts, or until the council formally decides it won't meet their needs.

What to expect: you may be contacted by a children's social worker, a transition team or a specialist adult team. Ask early who is responsible for your family, as it varies by council. Keep copies of everything.

The council must involve you

The Care Act gives families a clear right to be involved:

- **Transition assessments (section 65)**: the council must involve the young person, their parents and any carer, and anyone else they ask to be involved.
- **Adult assessments (section 9)**: the council must involve any carer, anyone the adult asks to be involved, and, if the adult lacks capacity, anyone who appears interested in their welfare.

Being a parent doesn't automatically make you a carer, but if you provide unpaid care, the council must involve you. The council still makes the final decisions. If you disagree, see "If you disagree" under Stage 2.

Education, Health and Care Plans (EHCPs) and age 25

If your son or daughter has an EHCP, it can continue up to age 25 if they are still in education or training and still need the support in it. It may end earlier, for example when they move into employment or leave education, but a plan should not simply stop at 18 or at the end of school.

Key points:

- From **Year 9 (age 13 to 14)**, annual EHCP reviews must include **preparing for adulthood**. The SEND Code of Practice (paragraph 7.38) sets out four areas: work and higher education (including supported employment and self-employment); independent living, including choice and control over where they live; friends, relationships and community; and being as healthy as possible.
- **A five-day package**. Many post-16 courses run only two or three days a week. For young people with an EHCP, councils should consider a full package of support across education, health and care covering **five days a week**, where that meets the young person's needs (paragraph 8.39). This is guidance councils must have regard to, not a guarantee, but they must consider it and be able to explain their decision. ***Ask at every review: "What's happening on the other days?"***

- An EHCP covers **education and training**. It is **separate from** an adult social care assessment, although it can record social care provision.

- Moving to adult services does not automatically end the EHCP. Ask for the two to work together.

Handing over: a checklist for the transition years

- [ ] Ask who your transition lead is, in both children's and adult services.
- [ ] Ask in writing for a transition assessment from Year 9 (age 13 - 14). Don't wait to be offered one.
- [ ] At EHCP reviews, ask about a five-day package across education, health and care.
- [ ] Make sure the EHCP annual review includes preparing for adulthood.
- [ ] Ask what will change at 16, 18 and 25.
- [ ] Start keeping notes for the needs assessment (see Stage 1).
- [ ] Ask about the carer's assessment for yourself (below).
- [ ] Ask what happens to any health-funded support at 18.

Carers' assessments: your rights as a parent or carer

If you care for your son or daughter, you have a right to be assessed in your own right.
This is called a **carer's assessment**.

- You can have one **whether or not** the person you care for has had an assessment, and regardless of your income or savings.

- There's **no minimum amount of care**, and you don't need to get Carer's Allowance. The council must assess any carer who appears to have needs for support.

- You can ask for it **separately** from your young person's assessment, so you can talk freely.

- It's your chance to say what care you are **willing and able** to provide, and for how long.

- Parents of **disabled children** can also have one, before the young person turns 18.

- The assessment looks at the impact of caring on your health, work, family life, wellbeing and plans for the future, and whether you are willing and able to continue.

- If you have eligible needs, the council must meet them. As a carer, you're eligible if caring is affecting your physical or mental health, or stopping you doing at least one important thing, such as working, seeing friends or family, looking after your home, or having time for yourself, and this has a significant impact on your wellbeing. (An adult needing care must be unable to achieve two or more outcomes; for carers, one is enough.) Support might include breaks, practical help or money.

What to expect: a conversation, often at home or by phone, that asks how caring affects you. Be honest about what you do and what happens when you are tired or unwell. Don't accept "we don't do those any more": councils must offer carer's assessments.

Stage 1: Needs assessment

What does it mean?

A needs assessment is an exploration of:

- how a person's disability affects everyday life
- what support they currently receive
- what outcomes matter to them
- what support may help them achieve those outcomes

The assessment should focus on the **whole person**, not simply their diagnosis.

Why does it matter?

Everything that follows is built on the assessment. If needs, aspirations and challenges are not accurately recorded, it can be hard to secure appropriate support later. Many experienced families describe it as the most important part of the process.

What action should I take?

Before the assessment, consider:

- What does a good day look like? A bad day?
- What does a good week look like?
- What support does the person already receive, including from family?
- What opportunities does the person want to access?
- What future aspirations do they have?

If possible, **keep notes for a week or two beforehand** (see the worksheet at the end of this section).

Getting the assessment started

- Ask in writing. Don't assume it will happen automatically. Your council's website will explain how to request an assessment. Chase it regularly.
- A social worker from the transitions team, children's services or the adult learning disability team will meet your young person and you, depending on how your council is organised.
- They gather information from school or college, work, the GP and others.
- A draft assessment is written, and should be sent to you to check.
- People with Down syndrome should be assessed by someone with learning disability expertise. Ask for this.
- Many councils use a "front door" or "three conversations" model, so the first conversation may be with a general worker. Persist until you reach the right team.

What to expect on the day

- **Who comes:** usually a social worker or assessor. It may be at home, in college or online.
- **How long:** often one to three hours, sometimes across more than one visit. There is no set length. Ask for more time if needed.
- **Who is involved:** the person with Down syndrome should be at the centre. They have the right to be involved, and to bring a family member, friend or advocate for support.
- **Advocate:** if your young person would find it very hard to understand or take part, and there's no suitable family member or friend to help, the council must provide an independent advocate. Ask about this before the assessment.
- **Your role:** support, add detail and fill gaps, but try not to answer for them. Let them speak first, and give them time.
- **Communication:** ask for the conversation to be adapted. Visual aids, Easy Read materials, Makaton, extra time or a familiar person can help.
- **Afterwards**: you should receive a written record of the assessment. Check it carefully and ask for changes if it is wrong or incomplete.

Tip: there's no legal deadline, but the council should complete the assessment within a reasonable time and tell you roughly how long it will take. The Local Government and Social Care Ombudsman normally expects assessments to be completed within 4 to 6 weeks. If there are long delays, ask in writing for an expected date.

Something that's easy to miss

It is natural to focus on what the person cannot do. A stronger assessment also explores:

- aspirations
- opportunities and participation
- barriers
- the support needed to achieve goals

Myth

"The assessment is about what services the council offers."

The assessment should focus on **needs and desired outcomes first**. Discussion of services comes later.



Understanding care outcomes

Assessors consider whether a person can achieve ten national outcomes. Thinking about these before an assessment will help you describe daily life clearly.

#	Outcome	A question to ask	Example of support
1	Managing and maintaining nutrition	Can they plan, shop for and cook meals safely, and remember to eat and drink?	Meal planning, shopping and cooking support
2	Maintaining personal hygiene	Do they wash, shower and clean teeth without being reminded? Do they need help managing periods?	Prompting, routine building, menstruation support for young women
3	Managing toilet needs	Can they manage independently, including away from home? Do they need help managing constipation?	Prompting, practical help, monitoring and managing constipation
4	Being appropriately clothed	Can they choose clothes suited to weather and activity?	Help choosing outfits, laundry routines
5	Making use of the home safely	Can they use appliances, lock doors and respond to emergencies?	Safety devices, supervision, skills practice
6	Maintaining a habitable home	Can they keep the home clean, safe and in good repair?	Cleaning and laundry support
7	Developing and maintaining relationships	Do they have friends and chances to see them?	Transport, groups, Personal Assistant
8	Work, training, education, volunteering	Would they like to work, volunteer or study?	Job coaching, travel training
9	Using facilities in the community	Can they travel, use shops and services, and attend appointments?	Travel training, accompaniment
10	Caring responsibilities for a child	Does the person have a child they care for?	Parenting support

Tip: health needs, medication and managing money aren't listed as outcomes, but include them. Physical and mental health is part of wellbeing, which the council must consider. They fit most easily under outcome 9, using the local community. Make sure everything is written into the assessment, and get a copy.

Example: Sam's plan. Sam's Care and Support Plan has six outcomes, written in his own words: "I want to eat a healthy diet", "I want to look after myself and be clean and presentable", "I want to wear clean, weather-appropriate clothes", "I want to live in a safe and clean home", "I want to see my friends more and join group activities" and "I want to work". Between them they cover nine of the ten outcomes.

How "unable to achieve" is defined

You do not need to be **completely** unable to do something. Under the regulations and statutory guidance, a person may be treated as **unable to achieve** an outcome if they:

- cannot do it **without assistance** from another person (this can include prompting or supervision)
- can do it but only with **significant pain, distress or anxiety**
- can do it but it **endangers or is likely to endanger their health or safety**, or that of others
- can do it but it takes them **significantly longer** than would normally be expected

If needs go up and down, the council must look at a long enough period to get an accurate picture. A good day shouldn't set the level of support. (Care and Support (Eligibility Criteria) Regulations 2015, regulation 2)

Outcome 1: Managing and maintaining nutrition

What does it mean?
The ability to obtain, prepare and consume food and drink safely. It is much more than being able to eat.

Questions to consider.
Can the person plan meals? Write a shopping list? Shop independently? Understand healthy eating? Prepare meals and use kitchen equipment safely? Remember to eat and drink?

What support might be needed?
Meal planning, shopping support, prompting, supervision, cooking and food safety support.

For example: someone who can make toast and simple lunches, but needs support to plan, shop for and cook a balanced evening meal. Without it, their meals become repetitive and limited.

Outcome 2: Maintaining personal hygiene

What does it mean?
Maintaining personal cleanliness and appearance.

Questions to consider.
Can the person shower and wash effectively? Brush their teeth thoroughly? Keep up hygiene routines? Recognise when hygiene is needed?

Something that's easy to miss: families often overlook prompting. **Prompting is support**. Needing repeated reminders does not mean someone is independent in this area.

For example: someone who can shower once started, but needs a prompt every day to begin, and a picture routine to finish. Many people with Down syndrome find multi-step routines hard to sequence without prompts or visual guides.

Outcome 3: Managing toilet needs

What does it mean?
Managing toileting safely, appropriately and with dignity.

Questions to consider.
Can the person get to the toilet independently? Manage personal hygiene? Recognise when they need help? Manage continence products if needed? What happens in unfamiliar places?

Support may include: prompting, supervision, practical assistance, and support in unfamiliar environments.

Outcome 4: Being appropriately clothed

What does it mean?
Choosing, wearing and managing clothing suited to weather, activities, social situations and cleanliness.

Questions to consider.
Can the person choose suitable clothes? Understand the weather? Know when clothes need washing? Store them appropriately?

For example: someone who loves choosing clothes, but would wear shorts in the snow, and needs help dressing for a work placement.

Outcome 5: Making use of the home safely

What does it mean?
Moving around and using the home safely.

Questions to consider.
Can the person use kitchen and electrical equipment safely? Lock doors and windows? Respond to emergencies, such as a smoke alarm? Stay home alone safely?

Potential support: risk management, visual prompts, safety devices, supervision, practice and skills development.

Outcome 6: Maintaining a habitable home environment

What does it mean?
Keeping a home safe, clean and suitable to live in. This is much broader than "doing housework". It includes laundry, cleaning, changing bedding, managing rubbish, maintaining kitchens and bathrooms, organising possessions, reporting repairs and using appliances safely.

Questions to consider.
Can they tidy, vacuum and clean bathrooms and kitchen surfaces? Wash dishes? Sort, wash, dry and put away laundry? Notice maintenance problems and report repairs?

Myth: *"He can use a washing machine, so he manages laundry."*
Laundry also involves recognising it needs doing, planning, completing it safely, putting items away and keeping up routines.

For example: someone who can work the washing machine, but relies on reminders to notice washing needs doing, and to dry it and put it away.

Outcome 7: Developing and maintaining relationships

What does it mean?
Building and maintaining friendships, family relationships, social connections and, where appropriate, romantic relationships.

Why does it matter?
Social isolation can seriously affect wellbeing. This is one of the most overlooked areas in assessments.

Questions to consider.
Does the person have friends? Chances to socialise? Need support to keep friendships going? Experience loneliness?

What support might help?
Transport, community activities, Personal Assistant support, social groups and leisure opportunities.

For example: someone who had friends at school but rarely sees anyone since leaving, and is becoming isolated. Support to get to a drama group and social events is added to their plan.

Outcome 8: Accessing work, training, education or volunteering

What does it mean?
Access to employment, volunteering, education, training and meaningful daytime opportunities.

Questions to consider.
Would the person like paid work, volunteering, training, college or work experience?
Support may include: travel training, job coaching, skills development, community access support and confidence building.

Something that's easy to miss: social care is not only about personal care. It can be essential to enabling work and volunteering.

For example: someone who wants to volunteer at a local football club, but isn't confident on buses. Travel support is added to their plan.

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

What does it mean?
Accessing and using shops, healthcare services, libraries, leisure centres, public transport and community activities.

Questions to consider.
Can the person travel independently? Attend appointments? Communicate their needs? Handle unfamiliar places? Stay safe, including from people who might take advantage of them?

For example: someone who can't yet read timetables or buy a ticket. Travel training lets them get to work and see friends.

Outcome 10: Carrying out caring responsibilities for a child

What does it mean?
This outcome applies only where the person has responsibility for a child. The assessment considers whether support needs affect their ability to fulfil those responsibilities.

This outcome will not apply to everyone, but the assessment should not make assumptions about anybody's life or future.

Easy to miss for people with Down syndrome

- **Prompting and supervision** count as support, even if they can do the task itself.
- **Multi-step tasks** can be hard to sequence without prompts or picture guides.
- **Hearing and vision** can affect how much they understand and take in.
- **Tiredness** from sleep apnoea or thyroid problems can change what they manage day-to-day.
- **Saying "yes"** to please, so ask open questions and check understanding.
- **Being very trusting**, which can leave them open to exploitation.
- **Changes over time**, such as losing skills or memory. Always raise these with the GP.

Wellbeing: the umbrella over the outcomes

The Care Act places great emphasis on **wellbeing**.

Councils must promote it, and it covers:

- personal dignity, including being treated 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
- participation in work, education, training or recreation
- social and economic wellbeing
- domestic, family and personal relationships
- suitability of living accommodation
- the person's contribution to society

These factors should run through the whole process. A **significant** impact on wellbeing means serious, noteworthy or profound: one area seriously affected, or several areas adding up.



Worksheet: preparing for the assessment

Use this over one to two weeks. It can be completed with the person with Down syndrome, using photos or symbols if that helps.

Area	A good day	A harder day	Support needed (who, how often)
Waking up, washing and dressing			
Meals and drinks			
Home tasks (laundry, cleaning)			
Getting out and about			
Friends and activities			
Work, college and volunteering			
Safety (home, road, strangers)			
Evenings and weekends			

Also note:

- What does the person want to do or achieve in the next one to three years?
- What do they enjoy? What are they proud of?
- What would happen if family support was not available tomorrow?
- Which tasks need reminding, supervision or help, even if they can do the task itself?
- Any health, sleep, sensory, hearing, vision or communication needs that affect daily life?
- Any changes over time, such as fatigue, memory or skills being lost? These should always be raised with a GP.

Stage 2: Eligibility

What does it mean?

After the assessment, the council decides whether the person has **eligible needs**. There is a national test, and all three of the following must apply:

1. The person's needs arise from or are related to a **physical or mental impairment or illness**.
2. As a result, they are **unable to achieve two or more** of the ten outcomes.
3. As a consequence, there is, or is likely to be, a **significant impact on their wellbeing**.

Down syndrome is a lifelong condition, so the first part of the test is met. The assessment then looks at the second and third parts.

At Down Syndrome UK, we believe people with Down syndrome will be eligible for care and support under the Care Act 2014. It is the assessment that shows how and why, so a clear, honest picture of daily life matters.

Questions to consider

- What support does family provide now?
- What would happen if that support was not available?
- Does the person achieve outcomes consistently, safely and with dignity?
- What is the impact on wellbeing?

What to expect

- The council should tell you its decision, in writing, with reasons.
- If it decides needs are eligible, it must meet them (after considering any financial contribution; see Stage 4).
- If it decides they are not eligible, it must explain why and give information and advice about other support.

If you disagree

- Ask for the decision and its reasons in writing.
- Ask for a review or reconsideration, and provide extra evidence (the worksheet, medical letters, college reports).
- Use the council's complaints procedure.
- If it is not resolved, you can take the complaint to the Local Government and Social Care Ombudsman.
- Down Syndrome UK (including Access Ava on our website), the DSUK 16+ parents Facebook group, Mencap, Citizens Advice and Contact can offer guidance.

Stage 3: Care and Support Plan

What does it mean?

A Care and Support Plan explains:

- eligible needs
- desired outcomes
- support arrangements
- how needs will be met

What can a plan include?

Examples include Personal Assistant support, community participation, travel training, employment support, volunteering support, social activities, independent living skills, housing support, short breaks and confidence-building opportunities. **No two plans should be identical**.

What a plan should include, and what it won't pay for

The plan should include your young person's eligible needs; the outcomes they want, in their own words; how each need will be met and who is responsible; the personal budget; **a contingency plan** (what happens if support breaks down); and when it will be reviewed.

It won't usually pay for everyday living costs such as food, rent and bills; accommodation and travel on family holidays; education, which belongs in the EHCP; or health care the NHS should provide.

A full life: not just college hours

- **Weekdays:** for young people with an EHCP, councils should consider a **five-day package** across education, health and care (see "EHCPs and age 25" above).

- **Evenings and weekends:** friendships and using the community, including leisure, are two of the ten outcomes. If your young person has eligible needs there, support should be available **when they need it, including evenings and weekends**. Loneliness often hits hardest outside college hours, so describe it in the assessment.

Making the plan work for you

- The plan should include **whatever is needed** to meet assessed needs.
- **Travel should be included.** There's no point funding support your young person can't get to.
- **Be creative.** For example, a weekend away with a PA once a quarter to practise independent living.
- PAs, day services or a mix: choose what suits your young person.
- Negotiate with the council about what you will accept, and get a copy of the final plan.

Myth

"A Care and Support Plan is about hours of care."

The focus should be on **outcomes**. Support is the means of achieving them.

What to expect

- You should be involved in drawing up the plan and receive a copy.
- The plan should show a personal budget (the cost of meeting needs). Part 2 explains this.
- You can ask to receive the budget as a direct payment and to arrange support yourself. Part 2 explains this.
- Plans should be reviewed, usually shortly after support starts and then at least once a year, and whenever circumstances change significantly.

Reviews

- A review looks at what's working well and which needs aren't being met.
- It isn't an excuse to cut support. Any reduction must be based on a proper review of needs, not on budgets.
- If support is cut, ask for the reasons in writing, and challenge it if needs haven't changed.

For example: a plan that includes travel training, volunteering and community activities, with the emphasis on participation and confidence rather than supervision alone.

Stage 4: Financial assessment

What does it mean?

Once needs are identified, the council may carry out a financial assessment to decide whether the person must contribute to the cost. Remember: this never affects whether needs are eligible.

The assessment considers:

- income
- benefits
- savings and capital
- **Disability Related Expenditure** (DRE): extra costs caused by disability that can be taken into account

Part 2 explains DRE and the **Minimum Income Guarantee** (MIG), the amount of income the person is allowed to keep.

Questions to consider

- Have all disability-related costs been identified?
- Have you been asked about DRE?
- Do you understand how any contribution was calculated?

Something that's easy to miss

Disability-related expenditure is sometimes not recorded in full, which can lead to higher contributions than necessary. Keep receipts and records of extra costs.

What to expect

- A form (or visit) asking for details of income, benefits and savings.
- A written charging decision showing how any contribution was calculated. You can ask for a breakdown and a review.

What comes next?

Once you understand the assessment process, the next topics are in Part 2: Funding Adult Life:

- Personal budgets
- Direct payments
- Employing Personal Assistants
- Disability Related Expenditure (DRE)
- Minimum Income Guarantee (MIG)
- Housing and support options (Part 3)

These often determine how support works in practice and what opportunities are available to the individual and their family.



DSUK
Down Syndrome UK

WITH YOU FOR THE JOURNEY

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