DSUK
Down Syndrome UK

Future Pathways

Transition Checklists: Approaching 16 and 18



Start the 16 checklist around age 14 - 15 and the 18 checklist around 16 - 17: most items take months, not weeks. Tick items off as you go.

This checklist is written for families in England. Social care, education and mental capacity law differ across the UK, so if you live in Wales, Scotland or Northern Ireland, use it only as a general prompt: separate guides for each nation are being produced. Where a key difference matters, it's flagged. Rules change, so confirm details with the organisations under Where to get help.

This is general information, shared in good faith from parents' experience. It is not financial or legal advice: always check with the right organisation and take professional advice before making decisions.

Which laws apply where

Nation	Key laws for adult life
England	Care Act 2014 (adult social care); Children and Families Act 2014 and the SEND Code of Practice (EHCPs, up to 25); Mental Capacity Act 2005 (from 16). Benefits: PIP and Universal Credit from DWP
Wales	Social Services and Well-being (Wales) Act 2014 (social care, with a weekly cap on charges); Additional Learning Needs and Education Tribunal (Wales) Act 2018 (Individual Development Plans instead of EHCPs); Mental Capacity Act 2005 (from 16). Benefits: PIP and Universal Credit from DWP
Scotland	Social Care (Self-directed Support) (Scotland) Act 2013; Education (Additional Support for Learning) (Scotland) Act 2004; Adults with Incapacity (Scotland) Act 2000 (guardianship and power of attorney from 16). Benefits: Adult Disability Payment from Social Security Scotland instead of PIP
Northern Ireland	Social care through Health and Social Care Trusts; special educational needs law for Northern Ireland; Mental Capacity Act (Northern Ireland) 2016 (only partly in force so far). Benefits: PIP from the Department for Communities

Checklist: approaching 16

The big changes at 16 are the move from DLA to PIP, becoming their DWP appointee, and the Mental Capacity Act starting to apply.



Benefits (DLA to PIP)

- ☐ Watch for the DWP letter inviting a PIP claim, sent shortly before the 16th birthday (Scotland: no PIP; Child Disability Payment continues to 18)
- ☐ Reply promptly to the PIP letter, because DLA stops if you don't
- ☐ Start a folder of PIP evidence: EHCP, school reports, GP and hospital letters, therapy reports, social care assessments
- ☐ Use the annual health check to build evidence: get needs such as hard ear wax or difficulty controlling body temperature recorded in their notes, and ask the GP to use legal terms such as 'severe mental impairment' (useful for council tax and Disability Related Expenditure)
- ☐ Keep a one-to-two week diary of the support needed with daily living and getting around, including bad days and prompting
- ☐ Ask a benefits adviser or charity to help with the PIP form and to check whether a face-to-face assessment can be adjusted or done at home
- ☐ Reply to HMRC's letter so Child Benefit continues if they stay in full-time non-advanced education (otherwise it stops on 31 August after the 16th birthday)
- ☐ In some cases they can claim Universal Credit in their own name from 16, but you'd lose Child Benefit. Get a full benefits check first, as it can reduce household income

DWP appointeeship



- ☐ Decide with the young person whether they can manage their own benefits; if not, plan to become their appointee
- ☐ Phone the PIP line when the invitation arrives and say you want to be appointee
- ☐ Prepare for the DWP visit or interview with you and the young person (form BF56)
- ☐ File the confirmation (BF57) safely; you'll need it for banks and other organisations
- ☐ Ask your bank how benefit payments can be received (appointee account, or account in the young person's name)
- ☐ Note that council benefits and Social Security Scotland need their own separate appointee arrangements
- ☐ Set up simple record-keeping for what the money is spent on

Education and EHCP



- ☐ Make sure transition planning has been part of every annual review since Year 9
- ☐ Agree the post-16 setting (school sixth form, college, specialist college, supported internship) and get it named in the EHCP
- ☐ If college is only two or three days a week, ask at the EHCP review about a five-day package across education, health and care: "What's happening on the other days?"
- ☐ Understand that EHCP rights pass to the young person after compulsory school age, and you can act for them if they lack capacity
- ☐ Ask about travel assistance for post-16 education from the council

Social care and housing



- ☐ Ask the council in writing for a Care Act transition assessment from Year 9 (age 13 - 14). There's no set age, and many councils won't start until 16 or 17 unless you ask
- ☐ Ask for a carer's assessment for yourself (parents of disabled children can have one before 18)
- ☐ Ask whether your council lets them join the housing register from 16

Health and GP



- ☐ Check they're on the GP's Learning Disability Register
- ☐ Book the annual health check (available from age 14) and ask for a Health Action Plan
- ☐ Make sure the annual check covers Down syndrome essentials: thyroid blood test, hearing, vision, heart, weight, sleep and coeliac symptoms
- ☐ Ask for a Reasonable Adjustments flag on their record (longer appointments, easy-read letters, contacting you)
- ☐ Ask for a Summary Care Record with additional information
- ☐ Agree with the GP how you'll be involved once they're 16, and record the young person's wishes
- ☐ Renew proxy access to online GP services, which may need their consent or a best-interests decision
- ☐ Ask the paediatrician when and how transfer to adult hospital services will happen
- ☐ Write or update a hospital passport

Mental capacity and decisions

- ☐ Learn the basics of the Mental Capacity Act, which applies from 16: capacity is presumed and judged decision by decision
- ☐ Start supported decision-making at home, using easy-read information and time to think
- ☐ Think about whether a Court of Protection property and affairs deputyship will be needed (you can apply from 16)
- ☐ Scotland only: consider guardianship or power of attorney, both possible from 16

Other

- ☐ Keep the National Insurance number letter safe
- ☐ Open or review a bank account suited to their abilities
- ☐ Register them to vote (possible from 16)
- ☐ Get proof-of-age ID such as a PASS card



Checklist: approaching 18

At 18 parental responsibility ends, so parents lose any automatic right to make decisions, even if their child lacks capacity. Start this list around 16 - 17, because legal arrangements and care assessments are slow.

Legal decision-making



- ☐ Understand that from 18 professionals make best-interests decisions and must consult you, but you can't consent on your child's behalf
- ☐ Find out whether your child has capacity to make a Lasting Power of Attorney (possible from 18); ask the GP or a solicitor for a capacity assessment
- ☐ If they can, make LPAs for property and financial affairs and for health and welfare (via the Office of the Public Guardian)
- ☐ If they can't, and they have (or will have) savings, an inheritance or other money beyond their benefits, apply to the Court of Protection for property and affairs deputyship, ideally before 18. If they only have benefits, an appointeeship may be enough
- ☐ Know that an appointeeship covers DWP benefits only, not bank accounts, savings, inheritance or property
- ☐ If they'll live in supported living or a care home with restrictions, ask the council whether a deprivation of liberty authorisation is needed. The legal test changed in June 2026 and further changes are planned, so check the current position
- ☐ Scotland only: guardianship or power of attorney under the Adults with Incapacity (Scotland) Act 2000

Adult social care



- ☐ If you haven't already, ask in writing for a Care Act transition assessment and chase it. Ask for an assessor with learning disability experience
- ☐ Ask for a carer's assessment for yourself. You can have it separately, and there's no minimum amount of care
- ☐ Ask about a personal budget and direct payments
- ☐ Check the assessment and Care and Support Plan include everything, including travel, money and medication support, and get copies
- ☐ Make sure the assessment covers friendships and social life, including support at evenings and weekends if that's when it's needed
- ☐ Prepare for a financial assessment, as adult care can be charged for based on your child's own income and savings

- ☐ Write the needs behind any disability-related costs into the assessment, then ask for an individual Disability Related Expenditure (DRE) assessment and keep receipts (for example extra heating, ear wax removal, private therapy)
- ☐ Explore day opportunities, supported employment, short breaks and future housing options
- ☐ If health needs are complex, ask whether an NHS Continuing Healthcare checklist should be done

Benefits



- ☐ Check whether Child Benefit stops at 18 or continues because they're in qualifying education
- ☐ Get a benefits check on claiming Universal Credit (with limited capability for work and work-related activity) or New Style ESA in their own name
- ☐ Check that your Carer's Allowance continues (they need the PIP daily living component)
- ☐ Tell DWP about any change of address or living arrangements
- ☐ Ask Social Security Scotland about the move from Child Disability Payment to Adult Disability Payment (Scotland only)

Money and household



- ☐ Apply to the council for the severe mental impairment council tax disregard: if they live alone, the home pays no council tax; if they live with you, it may mean a 25% discount. Also ask about the carer disregard and the Disabled Band Reduction
- ☐ If they live with you, agree a fair amount of board towards household costs. It comes out of their protected Minimum Income Guarantee
- ☐ Put their name on the council housing register if you haven't already, and ask for medical or welfare priority
- ☐ Review their bank account and who can operate it (LPA or deputyship usually needed for a parent to manage it)
- ☐ Apply for a Disabled Persons Railcard and disabled bus pass
- ☐ Consider a Blue Badge, and Motability if they get the PIP enhanced mobility component

Health and GP



- ☐ Confirm the transfer to adult hospital teams is complete and you know who to contact
- ☐ Keep annual health checks going and update the Health Action Plan

☐ Update the hospital passport, and give a copy to day services or carers

☐ Re-check GP proxy access and how you'll be involved in appointments

☐ Register with a new GP if they move to college, supported living or a care home

☐ Book the annual flu vaccine

☐ Ask the GP about ongoing monitoring for changes in memory, skills or behaviour as they get older

Your own planning



☐ Update your will

☐ Take advice from a STEP-member solicitor (Society of Trust and Estate Practitioners) on a disabled person's trust, so inheritance doesn't affect benefits or care funding

☐ If you're thinking of buying a home for your young person, get advice before you buy on whether to buy in their name, through a trust, or as their landlord

☐ Write a 'letter of wishes' or 'all about me' document so others know their routines, preferences and support needs

☐ Make sure someone else in the family knows where key documents are kept



Where to get help

Need	Who can help
Down syndrome-specific advice, benefits and transition guides	Down Syndrome UK, including Access Ava: downsyndromeuk.co.uk/parents/social-care Down's Syndrome Association helpline: downs-syndrome.org.uk
Peer support from other parents	Down Syndrome UK 16+ parents Facebook group: join the group Adult Social Care Warriors Facebook group: join the group. Lots of shared experience, but check any advice before
Benefits checks and form help	Citizens Advice: citizensadvice.org.uk Contact: contact.org.uk Scope: scope.org.uk Turn2us benefits calculator: benefits-calculator.turn2us.org.uk
Learning disability rights and social care	Mencap: mencap.org.uk
Carer's assessments and Carer's Allowance	Carers UK: carersuk.org
LPAs and deputyship	Office of the Public Guardian: gov.uk/government/organisations/office-of-the-public-guardian
Trusts, wills and Court of Protection	A STEP-member solicitor specialising in disability trusts and the Court of Protection. Find one at step.org
Scotland benefits and guardianship	Social Security Scotland: socialsecurity.gov.scot Office of the Public Guardian (Scotland): publicguardian-scotland.gov.uk
Complaints about the council	Local Government and Social Care Ombudsman: lgo.org.uk
Local Housing Allowance rates for your area	LHA Direct: lha-direct.voa.gov.uk
Shared ownership for people with a disability	My Safe Home, set up by David Abbey: mysafehome.info. T: 02476 402211. Free initial guidance: enquiries@mysafehome.info

Housing and supported living	DSUK's supported living video: watch on YouTube Learning Disability England's housing guide (with Housing LIN and ACE Anglia) Mencap's Housing Law Toolkit
Equality and human rights in housing	Equality Advisory and Support Service (EASS): 0808 800 0082

Please always check websites and helpline numbers are still current before relying on them.

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WITH YOU FOR THE JOURNEY

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