Transition to Adulthood

A practical guide for families affected by Kabuki syndrome in England and Wales

For families of a young person with Kabuki syndrome, the move from childhood to adulthood can feel like a particularly complicated transition.

For many years, parents and carers may have organised medical appointments, spoken to schools and professionals, managed benefits and finances, and made important decisions on their child's behalf. As a young person approaches adulthood, the legal framework around some of these things changes.

There is no single moment when everything changes. Different transitions happen at different ages and at different times. Planning early can make the process much easier.

This page provides a starting point for some of the things families may want to consider.

Where do I start?

From around age 14 onwards, it is worth beginning to think about:

- education, training and employment
- health and the move from children's to adult services
- friendships, relationships and community
- independent or supported living
- benefits and managing money
- decision-making and mental capacity
- Lasting Power of Attorney or Court of Protection arrangements
- wills, inheritance and trusts
- adult social care and support
- what your son or daughter wants their adult life to look like

Not everything on this page will apply to every person with Kabuki syndrome. Some young adults will be able to manage most or all of these areas independently. Others may need support with particular decisions, while some will require significant lifelong support.

The starting point should always be the individual young person, their abilities, wishes and aspirations.

Decision-making and mental capacity

One of the biggest changes for parents is understanding what happens to decision-making as their child becomes an adult.

The Mental Capacity Act 2005 applies in England and Wales to people aged 16 and over. Mental capacity is not simply something a person either has or does not have. It relates to a particular decision at a particular time.

Someone may, for example, be perfectly capable of deciding what they want to eat, where they want to go or who they want to spend time with, while needing support with a complicated financial or legal decision.

The law also says that a person should be supported to make their own decisions wherever possible.

At 18, a young person legally becomes an adult. Parents do not automatically retain the legal right to make decisions or manage money simply because their adult son or daughter has a learning disability.

The Ministry of Justice has produced an especially useful guide specifically for parents and carers of young people aged 14–25:

Making financial decisions for young people who lack capacity – parent and carer toolkit

There is also general information about the Mental Capacity Act here:

Mental Capacity Act – making decisions

Lasting Power of Attorney

If a young person has the mental capacity to understand and make a Lasting Power of Attorney (LPA), from age 18 they can choose people they trust to help them make decisions or, in certain circumstances, make decisions on their behalf.

There are two types:

Property and Financial Affairs – covering matters such as bank accounts, bills, benefits, investments and property.

Health and Welfare – covering matters such as healthcare, treatment, care and where the person lives.

A learning disability does not automatically prevent somebody from making an LPA. What matters is whether they have sufficient capacity to understand the decision to create the LPA.

An LPA must be the young person's own choice – a parent cannot simply create one on their behalf.

GOV.UK – Lasting Power of Attorney

What if my son or daughter cannot make an LPA?

If someone does not have the capacity to make an LPA and decisions need to be made about their property or finances, an application to the Court of Protection may be necessary.

The Court can make a decision itself or appoint somebody as a deputy to make certain ongoing decisions.

A property and financial affairs deputy might, for example, be authorised to manage savings, bank accounts or other financial matters.

Deputyship is different from being a parent, carer or DWP appointee. The Court decides what authority the deputy has.

As part of the process of applying for Deputyship it will be necessary for a Mental Capacity Assessment to be undertaken and a Form COP3 completed by the assessor. If your child has an appointed social worker they will normally carry out the assessment and complete Form COP3 for free. If this option is not available there are firms out there who employ qualified social workers but they will charge a fee currently in the range of £600 - £800.

It is also possible to apply for a Health & Welfare Deputyship to enable parents to make decisions about health, treatment and where their child should reside. Such applications used to be quite rare but recent case law has widened the circumstances where such an application might be appropriate. Currently such an application might be accepted where for example there have been issues with transition into adult social care, frequent changes of personnel (consultants, doctors, social workers etc), the need for numerous continuous health decisions, disagreements over the "best interests" of the child etc.

GOV.UK – Become a Court of Protection deputy

Useful tip: if you believe your child will be unable to manage significant financial assets when they reach 18, start investigating this well before their 18th birthday. The Government's parent and carer toolkit explains that a Court of Protection application can sometimes be made before 18 in preparation for adulthood.

Bank accounts, savings and Child Trust Funds

This is an area families can easily overlook.

Once a young person becomes an adult, being their parent does not automatically give you authority to access money or savings held in their name – even if you originally put the money there.

This can become particularly important where a young person has substantial savings, investments or a Child Trust Fund which matures at 18.

If the young person cannot manage the asset themselves, appropriate legal authority may be required.

The Government's parent and carer financial toolkit contains a specific section about Child Trust Funds and accessing a young person's money:

Financial decision-making and Child Trust Funds – parent and carer toolkit

Benefits and becoming an appointee

A DWP appointee is different from an attorney or deputy.

If someone is unable to manage their own benefits, another person – often a parent or carer – can apply to the Department for Work and Pensions to become their appointee.

The appointee can manage benefit claims and payments on the person's behalf.

However, being an appointee does not automatically give you authority over the person's other money, savings or bank accounts.

GOV.UK – Become an appointee for someone claiming benefits

DLA and PIP at 16

For families receiving Disability Living Allowance for a child, another important transition happens around 16.

In England and Wales, a child receiving DLA will normally be invited to apply for Personal Independence Payment (PIP) after turning 16. DLA does not simply continue automatically.

GOV.UK – What happens to DLA when your child turns 16

Depending on their circumstances, some young disabled people may also be eligible for Universal Credit, including in certain circumstances while in education.

GOV.UK – Universal Credit eligibility

Benefits rules can be complicated and change over time, so individual welfare-rights advice can be extremely valuable.

Wills and planning for the future

Parents and carers may also want to think about their own wills.

Simply leaving a large sum of money directly to a disabled son or daughter may not always be the most appropriate arrangement, particularly where they may have difficulty managing money themselves.

Families may therefore want specialist legal advice about:

- making or updating their will
- who should act as executors
- who they would trust to support their son or daughter in the future
- whether money should be left directly to their child
- whether a trust might be appropriate
- who could act as trustees
- how an inheritance could affect the person's wider financial circumstances

A solicitor experienced in wills and trusts for families with disabled beneficiaries can advise on the options.

Disabled Person's Trusts and Vulnerable Beneficiary Trusts

A trust allows money, property or investments to be held and managed by trustees for the benefit of another person.

For some families this can provide a way of making long-term financial provision for a disabled son or daughter without simply leaving them a large inheritance to manage alone.

There are special rules for certain trusts established for disabled or otherwise vulnerable beneficiaries, including particular tax treatment.

Trust law and taxation can be complicated and the most appropriate arrangement will depend upon the family's individual circumstances. Families should therefore obtain specialist legal and, where appropriate, financial or tax advice rather than setting up a trust without advice.

GOV.UK – Trusts for vulnerable people

GOV.UK – Trusts and taxes

Can a young person make their own will?

Some young adults with Kabuki syndrome may be capable of making their own will.

Capacity to make a will is not necessarily the same as the ability to manage every aspect of someone's finances.

Where someone cannot make a will themselves, in certain circumstances an application can be made to the Court of Protection for a statutory will.

GOV.UK – Making a statutory will on behalf of someone else

Specialist legal advice should be sought in this area.

Health and moving to adult services

Healthcare can change significantly during the transition to adulthood.

Parents who have spent years organising appointments and communicating with medical teams may find that adult services approach consent, confidentiality and decision-making differently.

It is worth asking each specialist team:

- When will transition to adult services begin?

- Which adult team will take over?
- Will there be a joint handover?
- Who will coordinate care where several specialties are involved?
- What happens if there is no equivalent adult specialist?
- What information will parents or carers be able to receive?
- What reasonable adjustments does the young person need?

Learning Disability Register and Annual Health Check

People aged 14 or over with a learning disability who are on their GP's Learning Disability Register can have an annual health check.

This can be particularly valuable during transition because it gives the GP an opportunity to build a detailed understanding of the young person's health before paediatric services end.

NHS – Annual health checks for people with a learning disability

Health and Care Passport

A Health and Care Passport can explain important information about a person to healthcare professionals, including communication needs, medication, medical conditions, reasonable adjustments and how they express pain or distress.

NHS England recommends health and care passports as good practice for people with a learning disability and autistic people.

NHS England – Health and Care Passports

Education and EHCPs after 18

An Education, Health and Care Plan does not automatically end when a young person turns 18 or 19.

For some young people an EHCP can continue beyond 19, potentially up to 25, where the statutory requirements continue to be met and further education or training is needed to achieve their agreed outcomes.

There is not, however, an automatic entitlement to remain in education or retain an EHCP until 25.

Preparing for Adulthood planning should start from Year 9 at the latest and should consider four broad areas:

- employment and further/higher education
- independent living
- friends, relationships and participation in the community
- being as healthy as possible

GOV.UK – SEND Code of Practice: 0–25 years

GOV.UK – EHCPs for 19–25 year olds

Adult social care

Where a young person is likely to need care and support after 18, families should not have to wait until their 18th birthday before adult social care is considered.

Under the Care Act, local authorities have duties around transition assessments where a child is likely to have needs for care and support after 18 and carrying out an assessment would be of significant benefit.

Transition planning should look beyond simply keeping somebody safe. It should consider their aspirations, independence and participation in adult life.

GOV.UK – Care Act: transition from children's to adult care and support

Families may want to ask about:

- a transition assessment
- a Care Act needs assessment
- personal budgets
- direct payments
- respite and support for carers
- supported living
- residential options
- community activities
- travel training
- support to access employment or volunteering

A simple transition checklist

From around 14

- ☐ Make sure your child is on their GP's Learning Disability Register if appropriate
- ☐ Begin Preparing for Adulthood planning through EHCP reviews
- ☐ Start discussing aspirations for education, work, relationships, independence and adult life
- ☐ Ask medical teams when transition to adult services will begin
- ☐ Start developing a Health and Care Passport

Around 16–17

- ☐ Understand the Mental Capacity Act and supported decision-making
- ☐ Review DLA/PIP arrangements
- ☐ Consider whether a DWP appointee will be needed
- ☐ Look at bank accounts, savings and any Child Trust Fund
- ☐ Investigate Universal Credit where appropriate
- ☐ Ask about transition to adult social care
- ☐ Review future education, college, employment or supported internship options
- ☐ Begin discussing whether an LPA may be appropriate at 18
- ☐ If your child is unlikely to have capacity to manage significant financial matters, investigate the Court of Protection process

Approaching 18

- ☐ Consider Lasting Power of Attorney where the young person has capacity and wishes to make one
- ☐ Consider Court of Protection/deputyship where legal authority will be required and the young person lacks capacity
- ☐ Make sure appropriate arrangements exist for managing benefits

- ☐ Review access to bank accounts and savings
- ☐ Confirm adult healthcare arrangements
- ☐ Confirm adult social-care arrangements where needed
- ☐ Check education and EHCP arrangements
- ☐ Update the Health and Care Passport

For parents and carers

- ☐ Make or review your own will
- ☐ Consider specialist advice about a Disabled Person's/Vulnerable Beneficiary Trust
- ☐ Think carefully about who could act as trustees
- ☐ Think about who could support your son or daughter if you were no longer able to
- ☐ Consider future housing and care
- ☐ Keep an accessible record of medical history, medication and key contacts
- ☐ Record communication needs, routines, preferences and reasonable adjustments
- ☐ Talk to siblings and other family members about future plans where appropriate
- ☐ Most importantly, involve the young person in planning their own future as much as possible

One final thought

Transition should not simply be about replacing the things parents currently do.

It is also an opportunity to ask a much bigger question:

What does a good adult life look like for this young person?

That might include further education, work or volunteering, friendships, relationships, hobbies, sport, travel, greater independence, supported living or simply having more choice and control over everyday life.

The answer will be different for every person with Kabuki syndrome.

Planning for adulthood should therefore be about more than services, benefits and legal arrangements. It should be about supporting each young person to have the fullest adult life possible.

Important: This information is intended as a general guide for families and is not legal, financial or benefits advice. Legal arrangements differ across the UK. Much of the legal information above, including the Mental Capacity Act, Lasting Powers of Attorney and Court of Protection, relates specifically to England and Wales. Families should obtain appropriate professional advice for their individual circumstances.

Recommended reading

There is a lot to think about as a young person approaches adulthood and it can be difficult to know where to start. These are some of the resources we think families may find particularly useful.

Making financial decisions for a young person who may lack capacity

The Ministry of Justice has produced a toolkit specifically for parents and carers of young people aged 14–25 who may lack the capacity to make some financial decisions.

It covers many of the questions families have as their child approaches adulthood, including:

- what changes when your child turns 18
- mental capacity and supporting a young person to make their own decisions

- accessing and managing bank accounts
- Child Trust Funds
- benefits and DWP appointees
- Lasting Powers of Attorney
- applying to the Court of Protection
- deputyship
- when parents may need formal legal authority to manage their child's finances

We particularly recommend reading this guide if your child is approaching 18.

Ministry of Justice – Making financial decisions for young people who lack capacity: a toolkit for parents and carers

Preparing for Adulthood

The Preparing for Adulthood programme provides information about the transition into adult life for young people with SEND, including education, employment, independent living, health, friendships and participation in the community.

Preparing for Adulthood

SEND Code of Practice

The statutory SEND Code of Practice explains the responsibilities of schools, colleges, local authorities and health services towards children and young people with SEND aged 0–25.

The sections covering Preparing for Adulthood from Year 9 onwards are particularly relevant for families approaching transition.

GOV.UK – SEND Code of Practice: 0 to 25 years

Mental Capacity

The Mental Capacity Act is central to understanding how decision-making changes as a young person becomes an adult.

A diagnosis of Kabuki syndrome or a learning disability does not, by itself, mean that somebody lacks capacity. Capacity should be considered in relation to the particular decision that needs to be made, and people should be given appropriate support to make their own decisions wherever possible.

GOV.UK – Mental Capacity Act: making decisions

Contact – advice for families with disabled children

Contact provides information and advice specifically for families with disabled children. Their resources cover benefits, education, social care, preparing for adulthood and many of the practical issues families encounter during transition.

Contact – Preparing for adult life

Mencap – advice and information

Mencap has accessible information about learning disability, benefits, social care, health, housing, employment and the Mental Capacity Act.

Mencap – Advice and support

A good place to start

If your son or daughter is approaching 18 and you are unsure about what will happen to their money, benefits or your ability to continue helping them manage their affairs, we particularly recommend starting with the Ministry of Justice parent and carer toolkit above.

It was written specifically for families facing these questions and provides a useful explanation of when informal support may be enough and when an LPA, DWP appointeeship or Court of Protection application might need to be considered.