Transition to Adulthood

A practical guide for families affected by Kabuki syndrome in Northern Ireland

For families of a young person with Kabuki syndrome, moving from childhood to adulthood can feel complicated. Parents and carers may have organised medical appointments, worked with schools, managed benefits and finances and helped with decisions for many years. As their child grows older, different legal rules and services begin to apply.

There is no single day when everything changes. Planning for school-leaving and adult life often begins around 14, disability benefits may change at 16, and many health, social care and legal arrangements change around 18. Planning early can help families avoid gaps in support.

Where do I start?

From around age 14, families may want to begin thinking about:

- education, college, training, employment and volunteering
- health and the move from children's to adult services
- friendships, relationships, recreation and community inclusion
- independent or supported living, housing and adult care
- benefits, banking, savings and Child Trust Funds
- decision-making, Enduring Powers of Attorney and possible controllership
- wills, inheritance, trusts and long-term planning
- the young person's own hopes, wishes and ambitions

Not everything will apply to every person with Kabuki syndrome. Some adults will manage much of their lives independently; others will need support with particular decisions or ongoing care. The starting point should always be their abilities, preferences and aspirations.

Decision-making and mental capacity

Northern Ireland has its own legal framework. The Mental Capacity Act 2005 used in England and Wales does not apply. Northern Ireland's Mental Capacity Act 2016 has been brought into force only in stages. Its first phase covered areas including deprivation of liberty, research and money and valuables in certain care settings. Do not assume that all provisions of the 2016 Act, including its proposed new LPA system, are available in practice.

A diagnosis of Kabuki syndrome or a learning disability does not automatically mean a young person is unable to decide. The relevant question is what decision they can understand and make, with appropriate information, communication adjustments and support. Capacity can vary according to the decision and circumstances.

Parents do not automatically acquire authority to manage all finances, give consent to healthcare or obtain confidential information when their son or daughter becomes an adult. Discuss a particular issue with the relevant professional and seek Northern Ireland legal advice where formal powers may be required.

Department of Health – Mental Capacity Act

Enduring Power of Attorney in Northern Ireland

Northern Ireland currently uses an Enduring Power of Attorney (EPA) for property and financial affairs, rather than the two types of Lasting Power of Attorney (LPA) used in England and Wales. An EPA can be made by an adult aged 18 or over who understands the nature and effect of granting it. It is their choice; a parent cannot make one on behalf of someone who lacks the required capacity.

The EPA can cover bank accounts, bills, investments, property or other financial matters, subject to its wording and any restrictions. It may operate before loss of capacity in accordance with its terms; if an attorney believes the donor is becoming mentally incapable of managing their affairs, the EPA must be registered through the High Court's Office of Care and Protection.

An EPA does not give authority to make healthcare or personal welfare decisions. Those decisions must be considered under the applicable Northern Ireland law and clinical consent framework. Speak to a solicitor about preparing an EPA and choosing suitable attorneys and safeguards.

nidirect – Managing your affairs and Enduring Power of Attorney

What if my son or daughter cannot make an EPA?

Where an adult lacks capacity to manage property or finances and no suitable EPA exists, a family member or another appropriate person may need to apply to the Office of Care and Protection (OCP) for the appointment of a controller. The OCP is part of the Family Division of the High Court and supervises controllers responsible for the financial affairs of adults unable to manage them themselves.

The court decides the scope of a controller's authority, which may cover managing accounts, savings and other property. Controllership is not the same as a DWP/Department for Communities benefits appointeeship, and it does not itself create general healthcare decision-making rights.

An application may require medical evidence and financial information, and costs may arise. Unlike England and Wales, this is not a Court of Protection deputyship application using form COP3. Obtain advice about the most proportionate option and whether a formal court order is necessary.

Useful tip: if substantial savings or a Child Trust Fund will become accessible at 18, investigate the legal position well beforehand rather than waiting for a bank or provider to refuse access.

Department of Justice – Office of Care and Protection

Bank accounts, savings and Child Trust Funds

Money held in the young person's own name belongs to them. Parents do not automatically retain the ability to operate accounts or withdraw savings because they opened the account, contributed money or provide daily care.

A Child Trust Fund normally matures at 18. Someone who can understand and manage their money may be able to access it independently, with practical support. Where they cannot, contact the provider early to ask what evidence of legal authority is required, and consider specialist Northern Ireland advice about controllership or another appropriate route.

Check whose name accounts are held in, when access rules change, which documents providers request and whether any savings may affect means-tested benefits. Avoid transferring or accessing money without proper authority.

Benefits and becoming an appointee

A benefits appointee may be authorised to act for a claimant who cannot manage their benefit affairs. This can include dealing with claims, reporting changes and receiving payments. In Northern Ireland, social security is administered through the Department for Communities and its relevant services, rather than simply assuming DWP processes and contact routes apply.

Being an appointee does not automatically authorise control of all bank accounts, inherited money or other assets. The benefit authority should assess whether an appointee is needed; being a parent alone is not enough.

nidirect – Benefits and financial support

DLA, PIP and Universal Credit

For children receiving Disability Living Allowance (DLA), transition to Personal Independence Payment (PIP) ordinarily occurs from 16. Families should read invitation letters carefully and follow the specified deadlines so DLA does not end unnecessarily while a PIP claim is being considered. PIP uses different criteria from DLA and is not guaranteed simply because DLA was awarded.

Some disabled young people may also be eligible for Universal Credit, subject to age, education, capability-for-work and other rules. Particular care is needed where a young person is studying, as eligibility before 18 or while in full-time education is restricted. Specialist benefits advice can help families understand the effect of a young person's claim on household benefits and other support.

Ask about appointeeship, bank account arrangements, evidence for a PIP claim, benefit reviews and any effects on Carer's Allowance or other household support. Rules and amounts change, so check current Northern Ireland guidance.

nidirect – Personal Independence Payment

nidirect – Universal Credit

Wills and planning for the future

Parents and carers may want to review their own wills and consider how financial provision would work if they were no longer able to provide support. Leaving a large sum directly to a disabled adult may not always be the best solution, particularly where that person has difficulty managing money or is receiving means-tested support.

Questions to discuss with a solicitor include who should act as executors, who could assist your child in the longer term, how property or savings should pass, whether a trust is suitable, and who should act as trustees. Discuss contingency plans, including if a nominated person becomes unable to help.

Disabled person's trusts and vulnerable beneficiary trusts

A trust can allow appointed trustees to hold and administer money or property for another person. Certain trusts for disabled or vulnerable beneficiaries can qualify for particular UK tax treatment, but the rules are technical and depend on the beneficiary and trust structure.

A specialist Northern Ireland solicitor familiar with private-client law and disabled beneficiaries can advise on the trust deed, inheritance, trustees' obligations and benefits consequences. Avoid setting one up without legal and, where appropriate, tax advice.

GOV.UK – Trusts for vulnerable people

Can a young person make their own will?

Some young adults with Kabuki syndrome will have the necessary capacity to make a will. That is a separate question from whether they need support with everyday finances. Generally, a will-maker must meet the applicable age and legal capacity requirements, and the will must be validly executed.

Northern Ireland should not be treated as having the same Court of Protection statutory-will procedure described for England and Wales. If a person cannot make their own will, obtain specialist Northern Ireland succession-law advice about what is legally possible and suitable.

Health and moving to adult services

Children's and adult healthcare services may work differently, including in consent, confidentiality and communication with parents. A planned transfer is particularly important where several specialties are involved, as can happen with Kabuki syndrome.

Ask each service:

- When will transition start and which adult team will take over?
- Will there be a joint appointment or handover summary?
- Who coordinates care when multiple consultants or services are involved?
- What happens if no equivalent adult specialist service exists?
- How will the young adult's own consent and communication needs be supported?
- What information may be shared with parents and carers?
- What reasonable adjustments, accessible information and appointment support are needed?

Learning-disability healthcare and health passports

Ask the GP practice and relevant Health and Social Care Trust what learning-disability health checks, reasonable adjustments and local services are available. Do not assume that the NHS England annual-health-check programme operates identically in Northern Ireland.

A health or hospital passport can summarise medical conditions, medicines, communication style, hearing or sensory needs, signs of pain or distress, important contacts and how best to support the young person. Keep it updated and accessible during handovers.

Education and moving on from school

Northern Ireland uses statements of special educational needs (SEN) and statutory transition planning, rather than England's Education, Health and Care Plans (EHCPs). For young people with statements, transition planning starts through annual reviews around age 14 and should be revisited as needs and aspirations change.

A transition plan should address education and training, suitable employment, accommodation, leisure, independence and relevant support. The Education Authority's transition service, the school, Careers Service and Health and Social Care Trust may all have roles in planning.

School provision and the statement do not automatically continue to 25 in the way some families may associate with English EHCPs. Ask early about the intended school-leaving date, further education options, reasonable adjustments, transport, specialist support and funding arrangements.

If the young person disagrees with an assessment or statement decision, seek independent advice about the applicable Northern Ireland SEN appeal routes and time limits.

Education Authority Northern Ireland

nidirect – Special educational needs

Adult social care and support

In Northern Ireland, Health and Social Care (HSC) Trusts provide or arrange social care alongside health services. Contact the relevant Trust before children's services end to ask for an adult-needs assessment and a coordinated transition plan. Ask when the adult learning-disability team will become involved and who is responsible for arranging support.

Planning should look beyond safety and personal care: discuss independent living, friendships, community activities, supported employment, housing, travel and the young person's long-term goals. Carers can ask about assessment of their own support needs and short-break options.

Depending on assessment and eligibility, support may include home support, day opportunities, respite, supported accommodation or direct payments that allow someone to arrange eligible care instead of having the Trust arrange it. Ask how direct payments can be managed if the young person needs help with finances.

nidirect – Direct payments for care

A simple transition checklist

From around 14

- ☐ Ask about the SEN transition plan at annual reviews and the named coordinator.
- ☐ Discuss college, training, work, friendship, housing and independent living aspirations.
- ☐ Ask health teams to begin planning adult-service handovers.
- ☐ Create or update a health/hospital passport and communication profile.
- ☐ Ask the HSC Trust when children's-to-adults transition planning should begin.

Around 16–17

- ☐ Respond to any DLA-to-PIP invitation and check deadlines.
- ☐ Ask whether a benefits appointee is necessary.
- ☐ Investigate Universal Credit only with advice about eligibility and household impact.
- ☐ Review bank accounts, savings and any Child Trust Fund.
- ☐ Explore supported decision-making and the young person's understanding of legal arrangements.
- ☐ Investigate future education/training and support after leaving school.
- ☐ Request adult social-care planning and carer-support information.

Approaching 18

- ☐ Consider an EPA if the young person has capacity and wishes to grant one.
- ☐ If formal financial authority will be needed and an EPA is not possible, ask about OCP controllership.
- ☐ Confirm arrangements for benefits, banking and savings.
- ☐ Check adult medical teams, consent and information-sharing arrangements.
- ☐ Confirm HSC Trust adult care, housing and community support where required.
- ☐ Review post-school placement, transport, funding and reasonable adjustments.
- ☐ Update health passport, key contacts and emergency information.

For parents and carers

- ☐ Make or review your own wills and consider specialist advice about trusts.

☐ Think about executors, trustees and who could support your child in future.

☐ Consider what happens if you become unwell or can no longer provide care.

☐ Keep accessible records of health history, medication and communication needs.

☐ Discuss plans with the young person and trusted family members where appropriate.

Recommended reading and useful organisations

These starting points are especially useful for families facing multiple changes at once:

Department of Health NI – Mental Capacity Act

Department of Justice – Office of Care and Protection

nidirect – Enduring Power of Attorney

Education Authority – transition and SEN

nidirect – PIP

nidirect – Direct payments

Contact – support for families with disabled children

Mencap Northern Ireland

Carers NI – advice and support

If your child is approaching 18 and you are unsure about who can manage their money, which legal authority is necessary, or how adult services will be arranged, speak to the appropriate Northern Ireland professional rather than relying on England-and-Wales forms or terminology.

One final thought

Transition should not simply be about replacing the things parents currently do. It is an opportunity to ask a bigger question: what does a good adult life look like for this young person? That might include further education, paid work or volunteering, friends, relationships, hobbies, sport, travel, supported living or greater choice in everyday life.

There will be different answers for different people with Kabuki syndrome. The aim is to plan around the individual's wishes, strengths, rights and support needs.

Important: This guide provides general information, not legal, financial, benefits or clinical advice. The law and implementation of policy can change, and individual circumstances differ. Check current Northern Ireland guidance and seek suitably qualified advice before making significant decisions.