Parent Carer Feedback on Mental Capacity, Court of Protection and Transition to Adulthood (SEND)

Purpose:
To share lived-experience feedback from parents and carers of young people with SEND about gaps in information, support and joined-up working around mental capacity, Court of Protection, deputyship and planning for adulthood, and to request clear, co-produced pathways and guidance.

1. Joined-up working and communication

Key feedback:

- Joined-up services: Parents want genuinely joined-up social care, health and education, with shared understanding and consistent messages about mental capacity, Court of Protection, deputyship and planning for adulthood.
- Clear conversations with the LA: Families need early, honest conversations about “what happens next” at 14+, 16 and 18—what changes legally, what decisions move to the young person, and what support is available.
- Health transition gap: There is no clear transition information from children’s to adult health services, especially around how capacity is assessed and who makes decisions.

Key asks:

- A single, co-produced local pathway for mental capacity, Court of Protection and deputyship, spanning education, health and social care.
- Named contact points in Adult Social Care and Health for mental capacity/Court of Protection queries.
- Regular joint information sessions (LA, NHS, legal/advocacy, parent carer forum) on these topics.

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2. Understanding mental capacity and decision-making

What the law says in brief (for your context section):

- Mental capacity is decision-specific and time-specific: a person may have capacity for some decisions but not others, and this can change over time.
- Under the Mental Capacity Act 2005 (MCA), a person is assumed to have capacity unless it is shown they lack it, and all practicable support must be given to help them decide before anyone decides for them.
- If someone lacks capacity for a specific decision, any decision made for them must be in their best interests, considering their wishes, feelings, values and the views of those who know them well.

Parent questions and concerns:

- Basic understanding:
  - What is mental capacity in plain language?
  - What affects mental capacity (e.g. learning disability, autism, mental illness, trauma, fluctuating conditions)?
  - What is the difference between mental health and mental capacity?

- Assessment and process:
  - How is capacity assessed, especially for non-verbal young people?
  - Who carries out capacity assessments (social workers, doctors, other professionals)?
  - What happens if a young person makes “unwise” or risky decisions—how does the MCA treat this?

- Conditions and overlap:
  - What is classed as a “mental disorder” or “impairment of the mind or brain” under the MCA?
  - How does the MCA apply where there is PTSD, autism, severe learning disability or disabling mental health needs?

Key asks:

- Plain English, SEND-specific guidance on mental capacity, with examples for non-verbal and complex needs.
- Clear explanation of capacity assessments—who does them, how they are recorded, and how parents are involved.
- Training for professionals so messages to families are consistent and lawful.

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3. Parental rights, best interests and post-16/18 decisions

Legal context in brief:

- At 16, a young person is generally presumed to have capacity to make their own decisions unless assessed otherwise under the MCA.
- If they lack capacity for a specific decision and there is no relevant power of attorney or deputy, professionals must decide in the person's best interests, taking into account the views of family and others who know them well.
- The Court of Protection can decide whether someone has capacity, resolve disputes about best interests, and appoint deputies to make decisions for someone who lacks capacity.")
- Deputies must act in the person's best interests and are supervised by the Court and the Office of the Public Guardian.

Parent questions and concerns:

- Parental role after 16/18:
  - Without Power of Attorney or Court of Protection, what rights do parents have in decision-making?
  - How are parents' views considered in best interests decisions?
  - What is "parental responsibility override" in practice?

- Best interests:

  - What are “best interests” in law, and how are they decided?
  - How do best interests decisions affect parents and carers day to day (e.g. medical treatment, living arrangements, education, finances)?

- Deputyship and Court of Protection:
  - What is the process to become a deputy (property & financial affairs, personal welfare)?
  - When is it the right time to apply to the Court of Protection?
  - What are the pros and cons of deputyship versus Lasting Power of Attorney (where possible)?

Key asks:

- Clear local explanation of parental rights and limits after 16 and 18, in the context of the MCA.
- Step-by-step guides (with timelines and costs) for:
  - Applying for deputyship.
  - Using or setting up Lasting Power of Attorney where the young person has capacity.
- Standard practice that parents are routinely consulted and recorded as key consultees in best interests decisions.

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4. Money, bank accounts and child trust funds

Parent questions and concerns:

- Awareness and options:
  - Parents are often unaware of Power of Attorney, guardianship and deputyship until crisis point.
  - How can parents legally access Child Trust Funds or savings where the young person lacks capacity?
  - What are safe, legal options for bank accounts for non-verbal young people or those who cannot manage money independently?

Key asks:

- Joint guidance from the LA, local banks/credit unions and advice services on:
  - Managing money for young people who lack capacity.
  - Accessing Child Trust Funds where capacity is in question.
- Workshops or clinics on financial decision-making, with legal and financial experts.

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5. Health, adult services and DNACPR

Parent questions and concerns:

- Adult health input:
  - What input do adult health services provide for young people with complex SEND and limited capacity?
  - How do adult services work with families on best interests decisions?

- Information duties:
  - What information should GPs and health professionals give parents/carers about capacity and consent?
  - How is capacity assessed in health settings, especially for non-verbal young people?

- Do Not Resuscitate (DNACPR):
  - What are the policies and safeguards around DNACPR decisions?
  - How are parents involved in DNACPR discussions and best interests decisions?
  - How are decisions recorded and reviewed?

Key asks:

- Clear local protocol for involving families in health capacity assessments and best interests decisions.

- Transparent DNACPR policy summary for SEND families, including rights to be consulted and to challenge decisions.

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6. Planning for the future and whole-family impact

Parent questions and concerns:

- Future planning:
  - How can parents plan for the whole immediate family’s future, especially where there are no other relatives to care for their adult child when they die?
  - What legal and practical options exist (e.g. deputyship, trusts, supported living, advocacy)?

- Preparing for adulthood:
  - Is “Preparing for Adulthood” really preparing for life for young people with complex SEND?
  - Current systems feel designed for “typical” young adults, not those with severe learning disabilities and non-verbal autism.

Key asks:

- Integrated future-planning offer (social care, health, legal/financial advice) starting early—ideally from Year 9.
- Specific resources for families with no wider support network, including contingency planning and advocacy.

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7. Concrete requests to Adult Social Care, Health and the LA

1. Co-produce a local Mental Capacity and Court of Protection pathway with parent carers, covering ages 14–25 and beyond.

2. Develop clear, accessible information (print, online, workshops) on:
   - Mental capacity and best interests.
   - Parental rights post-16/18.
   - Power of Attorney, deputyship and Court of Protection.
   - Money management and Child Trust Funds.
3. Name lead contacts in Adult Social Care and Health for mental capacity/Court of Protection queries.
4. Embed training for social workers, health professionals and education staff on the MCA and working with families.
5. Commit to regular joint sessions with the Parent Carer Forum to review how this is working and update resources.