

Decision making and the Mental Capacity Act for young people with special educational needs or disabilities

This is a briefing note for staff in education, health and social care working with young people (age 14+). It aims to fill a gap noted by families, carers' organisations and Mental Capacity Act (MCA) lead officers. It includes suggestions for resources you may wish to offer to young people and their families (including foster families).

Most young people start to make more choices and decisions for themselves as a matter of course and this is recognised and accepted by their families and the services that work with them. Encouraging and supporting this is enshrined in the Children and Families Act and all the related practice guidance, as well as NICE guidance on transition¹.

More deliberate effort is needed to support some young people to make and assert choices. One of the surprises that families of some young people describe is learning that from the age of 16 young people are expected to make decisions (such as consenting to health care) themselves – with support as needed – rather than parents deciding. Some young people will be unable to make some decisions; they and their families need to understand that the MCA 'best interests' processes will then be used.

Together 4 Short Lives² say *"The new way that decisions about your care are made once you are an adult [means] the emphasis moves away from your parents/carers making decisions in your best interests to you making them for yourself. This could feel quite strange for you and your parents and you may need to discuss this change [...] – perhaps exploring areas of your life where you would like to take more responsibility. You are likely to still be supported by your family but you'll be asked for your views more and more. [...] As well as support being available to you, make sure that your parents are supported to take a step back from managing your care themselves."*

It is a good idea to raise this topic with young people and families early, as we want children and young people to be as independent as possible. More formal discussions should happen from Year 9 onwards, so that they know what to expect. There are some good guides for families, such as:

- 'Decision Making, Confidentiality and Sharing Information: A Guide for Parents' from Cerebra: <http://w3.cerebra.org.uk/help-and-information/guides-for-parents/decision-making-confidentiality-and-sharing-information/>
- 'Factsheet: The Mental Capacity Act 2005 and Supported Decision Making' from Preparing for Adulthood: <http://www.preparingforadulthood.org.uk/resources/all-resources/pfa-factsheet-the-mental-capacity-act-2005-and-supported-decision-making>

¹ <https://www.nice.org.uk/guidance/NG43>

²

http://www.togetherforshortlives.org.uk/professionals/resources/9606_moving_to_adult_services_what_to_expect

- 'My life, my support, my choice' from Think Local Act Personal and National Voices: <http://www.thinklocalactpersonal.org.uk/Latest/My-life-my-support-my-choice-a-narrative-for-person-centred-coordinated-care-and-support-for-children-and-young-people-with-complex-lives/>

There are three issues you could raise specifically with young people and their families:

1. Supporting young people to make decisions for themselves if they can
2. The right of young people with capacity to make decisions and take risks that others may see as unwise
3. Best interests decision making for young people who lack capacity to make a specific decision at a specific time.

Supporting decision making

Some young people need a little help to understand and make decisions; others need a lot of support to understand options, retain and weigh up information and express their preferences. The MCA makes it clear that people have a right to 'all practicable' support to understand and make their decisions, before they are assessed as lacking capacity to do so. A range of free resources are available, such as person-centred thinking tools to support communication and decision making:

<http://www.helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/decision-making-agreement/>

Right to make unwise decisions

Most parents have to face up to their teenage sons and daughters starting to make choices that make parents uncomfortable – from clothing through hair dye to body piercings and relationships. Some young disabled people miss out on the chance to make such choices because they depend on others for both awareness of options and the ability to act on them. This blog from two parents explains why it is important to allow and support children and young people to take risks:

<http://www.downsideup.com/2012/11/why-take-chance-letting-your-child-take.html>

The Preparing for Adulthood programme offers a series of videos of young people talking about issues such as drugs, alcohol, sex and relationships:

https://www.youtube.com/playlist?list=PL-J_NEPDngHyY0LstrQX0Lvv0-VZ2LwjB

Best interests decisions

Parents and carers who have always made important decisions for their son or daughter need to know in advance how this will change – that they will be fully involved and that their understanding and knowledge of their son or daughter will always be vital and respected. The young person will also be informed and involved as much as possible. The decision will be made by the relevant decision maker (such as a health professional or social worker), following the process of involvement.

There is a useful guide for families about the MCA, including deputyship and appointeeship. There are videos of family members talking about different decisions and about best interests decision making: <http://www.hft.org.uk/Supporting-people/Family-carers/Resources/Using-the-Mental-Capacity-Act/>

For more useful resources and information see:

www.ndti.org.uk/uploads/files/NDTi_MCA_Useful_Information_and_Links.pdf