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Decision Making Toolkit

A practical guide to supporting young people with special educational needs and disabilities to make their own decisions and to be engaged in the best interests¹ decision making process



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1. Best interests decisions where a young person is assessed as lacking capacity in line with the Mental Capacity Act 2005

Acknowledgements

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This toolkit is designed to support social workers, health practitioners, school and college staff, parent carers, families and anyone working directly with children and young people with special educational needs and disabilities (SEND), to support young people to make their own decisions and to participate as fully as possible in decisions made on their behalf in line with the requirements of the Mental Capacity Act 2005.

For more information on resources, tools and support please contact Amanda Harvey, Assistant Director at the Council for Disabled Children at AHarvey@ncb.org.uk.

Introduction

There is a wide range of decisions that children and young people need to make or to be involved in throughout their lives. The level of their involvement and whether they are making decisions for themselves or someone is making a decision on their behalf may depend on a number of factors such as their age, their understanding, the significance of the decision and whether the child or young person has capacity.

For very young children decisions will be made on their behalf by their parent carer or someone with parental responsibility. However, as children move towards adulthood gradually more and more decisions can potentially be made by them, and in some specific circumstances their own decision making rights may supercede those of their parents.

When we are trying to decide whether a child or young person under the age of 16 is mature enough to make decisions for themselves we refer to Gillick Competence, which is based on a child being able to understand a decision, what it involves and to retain the information and communicate their decision. You can read more about Gillick competency here: <https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/chapter-7.pdf>.

The decision making rights of young people over the age of 16 are subject to whether they have capacity under the Mental Capacity Act 2005 (MCA). There is an assumption that a young person has capacity unless there is a reasonable belief that they do not, at which point an assessment of capacity should take place.

In addition, for adults over the age of 18 the Deprivation of Liberty Safeguards (DoLS) also apply. The DoLS were introduced in April 2009 as part of the implementation of the MCA. The aim of DoLS is to ensure that there is better legal and administrative protection for those who may lack capacity to consent to the care they are receiving, including where they live and how they are cared for.

There is a range of circumstances in which a young person who lacks capacity may need to be deprived of their liberty in order to provide appropriate care and/or treatment. For young people aged 16-17 case law² tells us that parents cannot consent to what would otherwise constitute a deprivation of the young person's liberty. Where parents cannot consent to deprivation of liberty the local authority will have to seek permission from the Court of Protection in order to lawfully deprive a young person of their liberty. This is an additional safeguard for young people as the Court will only grant permission if it is in the young person's best interests.

The Department of Health has asked The Law Commission to review the existing DoLS system and it is likely that there will be recommendations for the system to extend to 16 and 17 year olds in the future. The final report and draft Bill are due to be completed in March 2017. You can find out more information on this work on the [Law Commission website](#).

The Mental Capacity Act 2005 (MCA)

The MCA applies to everyone over the age of 16 and is based on the fact that individuals may or may not have the capacity to make a single decision at a single time.

"The Act is intended to be enabling and supportive of people who lack capacity, not restricting or controlling of their lives. It aims to protect people who lack capacity to make particular decisions, but also to maximise their ability to make decisions, or to participate in decision making, as far as they are able to do so.

The five statutory principles are:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action."³

For more information on the MCA you can download the Preparing for Adulthood programme's free factsheet: <http://www.preparingforadulthood.org.uk/resources/all-resources/pfa-factsheet-the-mental-capacity-act-2005-and-supported-decision-making>

It is also important to note that where mental capacity is an issue, the Mental Capacity Act 2005 applies; where mental health is a concern but the young person has capacity under the MCA, treatment can be given under the Mental Health Act – For more information on the MHA you can download the MHA Code of Practice here: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/435512/MHA_Code_of_Practice.PDF

³ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

What is decision making?

Making a decision is a complex process made up of several different phases which most of us carry out subconsciously hundreds of times over the course of a day. Some decisions are small and the consequence of the decision may be less significant for example:

- whether to have tea or coffee with breakfast
- whether to wear a jumper or a coat to stay warm
- whether to take the train, a bus or to drive

Reflective activity:

Consider a small decision you have made recently, think about the process you went through with particular attention to the following:

- *Why did you need to make a decision?*
- *What information did you receive? (when, from where)*
- *What did you do with the information?*
- *Did you ask anyone's advice?*
- *What were your constraints? (e.g. budget)*

This is the process that we need to support a young person to go through when they have a decision to make, subject to their capacity to do so under the MCA.

Principle 1 of the MCA tells us that we must assume that a person has capacity until it is established that they lack capacity. Principle 2 states that a person is not to be treated as unable to make a decision unless all practicable steps to help them do so have been taken without success.

“The more young people get involved they will learn gradually to make decisions. Young people need to be encouraged or it will be scary when they turn 16.”

Young person, EPIC

It is important to remember that decision making is a skill and if a young person has not been taught that skill and not had an opportunity to practice it they may appear to lack capacity when in reality they need to be supported to go through the decision making process.

The section 19 principles in the Children and Families Act 2014 state that local authorities must have regard to the importance of participating ‘as fully as possible’ in decision making and the importance of information and support to assist participation. Young people will need to be supported to develop the same skills in order to engage in strategic decision making as they will to make individual decisions about their own lives.

The ability to make a decision: things to consider

- Does the person have a general understanding of what decision they need to make and why they need to make it?
- Does the person have a general understanding of the likely consequences of making, or not making, this decision?
- Is the person able to understand, retain, use and weigh up the information relevant to this decision?
- Can the person communicate their decision (by talking, using sign language or any other means)? Would the services of a professional (such as a speech and language therapist) be helpful?

Larger decisions may have more significant consequences. They are, however, often made up of a number of smaller decisions. Capacity is based on a single decision at a single time which means that a young person may have capacity to make some of the smaller decisions which contribute to a larger one.

The Children and Families Act 2014 identified a number of decisions in relation to Education, Health and Care plans (EHC plans). The specific decision making rights which apply to young people directly from the end of compulsory school age (16), are:

- the right to request an assessment for an EHC plan (which they can do at any time up to their 25th birthday)
- the right to make representations about the content of their EHC plan
- the right to request that a particular institution is named in their EHC plan
- the right to request a Personal Budget for elements of an EHC plan
- the right to appeal to the First-tier Tribunal (SEN and Disability) about decisions concerning their EHC plan

If we take the example of a young person deciding on the institution they want named in their EHC plan we can acknowledge that this is a large decision which may have significant consequences. However, there may be a number of smaller decisions which contribute to this such as:

- What do they want to study?
- Who do they want to study with? (e.g. existing friendship groups)
- Where do they want to live? (e.g. with family, near family, in their local community, at a college)

It is entirely possible that a young person could have the capacity to decide what they want to study whilst at the same time lacking the capacity to decide the best institution to meet their needs.

Where a young person is assessed as lacking capacity to make any of the decisions in relation to their EHC plan, as set out above, the SEND code of practice: 0-25 years⁴ states that:

“In cases where a person lacks mental capacity to make a particular decision, that decision will be taken by a representative on their behalf. The representative will be a deputy appointed by the Court of Protection, or a person who has a lasting or enduring power of attorney for the person.

In the case of a young person who does not have such a representative, the decision will be taken by the young person’s parent.”

It is therefore important that parents are supported to go through a best interests decision making process to ensure young people are as involved as possible and that their views, wishes and feelings are taken into consideration in any decision made on their behalf.

Assessing capacity

The MCA code of practice⁵ describes the test of capacity as a two-stage assessment that involves asking:

1. Is there an impairment of, or disturbance in the functioning of a person’s mind or brain (such as a learning disability or a mental health problem)?
2. If so, is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision?

If the first stage of the test of capacity is met, the second test requires the individual assessing capacity to show that the impairment or disturbance of the brain or mind prevents the young person from being able to make the decision in question at that time. This is a functional test focusing on how the decision is made, rather than the outcome or the consequence of the decision.

Principle 3 states that a person is not to be treated as unable to make a decision merely because they make an unwise decision.



⁴ - <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

⁵ - https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

Practical tools that support young people to develop decision making skills and be involved in decision making

What	Where
<p><i>Training for young people</i></p> <p>Developed by the CDC participation team, Making Ourselves Heard and in partnership with disabled young people, this training will help you to help children and young people understand the changes to SEND law and their right to be involved in decisions about their support. The training focuses on four key areas prioritised by young people:</p> <ul style="list-style-type: none"> • Education, Health and Care Plans • post-16 decision making • the Local Offer • personal budgets 	<p>https://councilfordisabledchildren.org.uk/making-ourselves-heard/resources/your-rights-your-future-toolkit</p>
<p><i>Information on young people's rights</i></p> <p>In relation to making decisions and choices about their healthcare.</p>	<p>http://www.getyourrights.org/</p>
<p><i>Activity: 'Why is it important to make a choice?'</i></p> <ul style="list-style-type: none"> • Discussion activity considering different choices made such as what to have for breakfast • Then swap choices with another person in the group • Think about: <ul style="list-style-type: none"> ○ what it would be like to have that person's choice instead of your own; ○ how would it feel if you never got to make that choice again and you had that for breakfast every day forever • Explore what young people would need to do/say if someone asked them to follow a choice they didn't like. 	<p>Contribution from a Local Authority delegate at training event.</p>

Making decisions about your SEND support fact sheet, Council for Disabled Children

[https://
councilfordisabledchildren.
org.uk/help-resources/
resources/making-
decisions-easyread-guide](https://councilfordisabledchildren.org.uk/help-resources/resources/making-decisions-easyread-guide)

Hear us out! VIPER guide to participation in decision making.

[https://
councilfordisabledchildren.
org.uk/help-resources/
resources/viper-findings-
hear-us-out](https://councilfordisabledchildren.org.uk/help-resources/resources/viper-findings-hear-us-out)

Best interests decision making

One of the key principles of the Act is that any act done for, or any decision made on behalf of a person who lacks capacity must be done, or made, in that person's best interests. That is the same whether the person making the decision or acting is a family carer, a paid care worker, an attorney, a court-appointed deputy, or a healthcare professional, and whether the decision is a minor issue – like what to wear – or a major issue, like whether to provide particular healthcare. As long as these acts or decisions are in the best interests of the person who lacks capacity to make the decision for themselves, or to consent to acts concerned with their care or treatment, then the decision maker or carer will be protected from liability.”

The Mental Capacity Act 2005 Code of Practice Chapter 5

This part of the tool is designed to support professionals, working with young people, to explain the best interests decision making process and to use the best interests checklist, as set out in the Mental Capacity Act 2005 Code of Practice, to ensure that the young person's views wishes and feelings are central to any decision being made on their behalf. Working out what is in someone's best interests cannot be based simply on someone's age, appearance, condition or behaviour.



Best interests decision making tool

Name:

Date of Birth:

What is the decision that needs to be made?



Where a young person lacks capacity to make a decision there are a number of things to consider before beginning the process:

Does the young person have a Lasting Power of Attorney (LPA) or a Court appointed deputy who has authority to make the decision?



NO



YES

The LPA or deputy should make a best interests decision on the young person's behalf

Has the young person made an Advance Decision to refuse treatment (where the decision relates to medical treatment)?



NO



YES

The young person's advance decision should be respected

Is it likely the young person will regain capacity in relation to this decision? If so, can the decision wait until they regain mental capacity?



NO



YES

The decision should be postponed until the young person is able to make the decision for themselves

Now it's time for a best interest decision

What are the views of other people close to the young person?

- Where practical and appropriate, consult others for their views about the young person's best interests and to see if they have any information about the person's wishes and feelings, beliefs and values
- Try to consult anyone previously named by the young person in relation to the decision in question or similar issues; anyone engaged in caring for the person – close relatives, friends; or others who take an interest in the person's welfare
- For decisions about major medical treatment or where the person should live and where there is no-one who fits into any of the above categories, an Independent Mental Capacity Advocate (IMCA) must be consulted.
- Remember that the person who lacks the capacity to make the decision or act for themselves still has a right to keep their affairs private – so it would not be right to share every piece of information with everyone.

Least restrictive option

All relevant circumstances should be considered when working out someone's best interests.

Avoid restricting the person's rights, and see if there are other options that may be less restrictive.

Identifying the least restrictive option.*

A young person with an EHC plan aged 17 is attending a mainstream college in his local community. The college is on a busy main road and the young person has very limited road safety awareness. They also have a history of trying to leave the college to go home when feeling stressed or anxious. The young person lacks capacity under the MCA and a best interests decision needs to be made on the least restrictive way to keep the young person safe and to ensure they are able to engage fully in the curriculum.

There are a number of options that the college are considering with the young person's parents and involving the young person as much as possible. The options include:

1. A 1:1 support worker to be with the young person from the moment they enter the college site in the morning to the moment they leave; *this is the parent's preferred option however the college know that the young person values their independence within the college environment and enjoys the freedom of being able to move between classes and enjoy lunch independently.*
2. That external gates are kept locked once the young person is inside the college; *this would be quite challenging for the college and would also impact on the other students as well as posing potential health and safety risks.*
3. An alert system could be introduced which would involve the young person being equipped with a 'buddy tracker' style device which could alert a designated person who is onsite when the young person is outside of the college building at times when that would not be expected. This would result in a member of staff attending the entry/exit point to the college to ensure the young person is safe.

After a number of meetings and discussions involving the young person and considering their views it is agreed that option 3 is the least restrictive option and is in the young person's best interests.

It is also important to note that some options may also amount to a deprivation of a young person's liberty and the DoLS process would need to be followed.

* Please note this an example and all cases should be considered based on individual circumstances.

Weigh up all of these factors in order to work out what is in the young person's best interests.

Record the decision that has been made



Name:

Signature:

Relationship to the young person:

Job Title:

Organisation:

Date:



About the Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with Special Educational Needs (SEN) and their families. The CDC membership is made up of a variety of professional, voluntary and statutory organisations, including disabled young people and parent representatives. CDC's broad based membership and extensive networks of contacts provides a unique overview of current issues. It also enables us to promote collaborative and partnership working among organisations.

CDC hosts the following networks and projects:

- IASS Network
- Independent Support
- Making Ourselves Heard
- Special Educational Consortium
- Transition Information Network

If you would like to share good practice on any of the issues set out in this publication please contact Amanda Harvey at aharvey@ncb.org.uk



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