

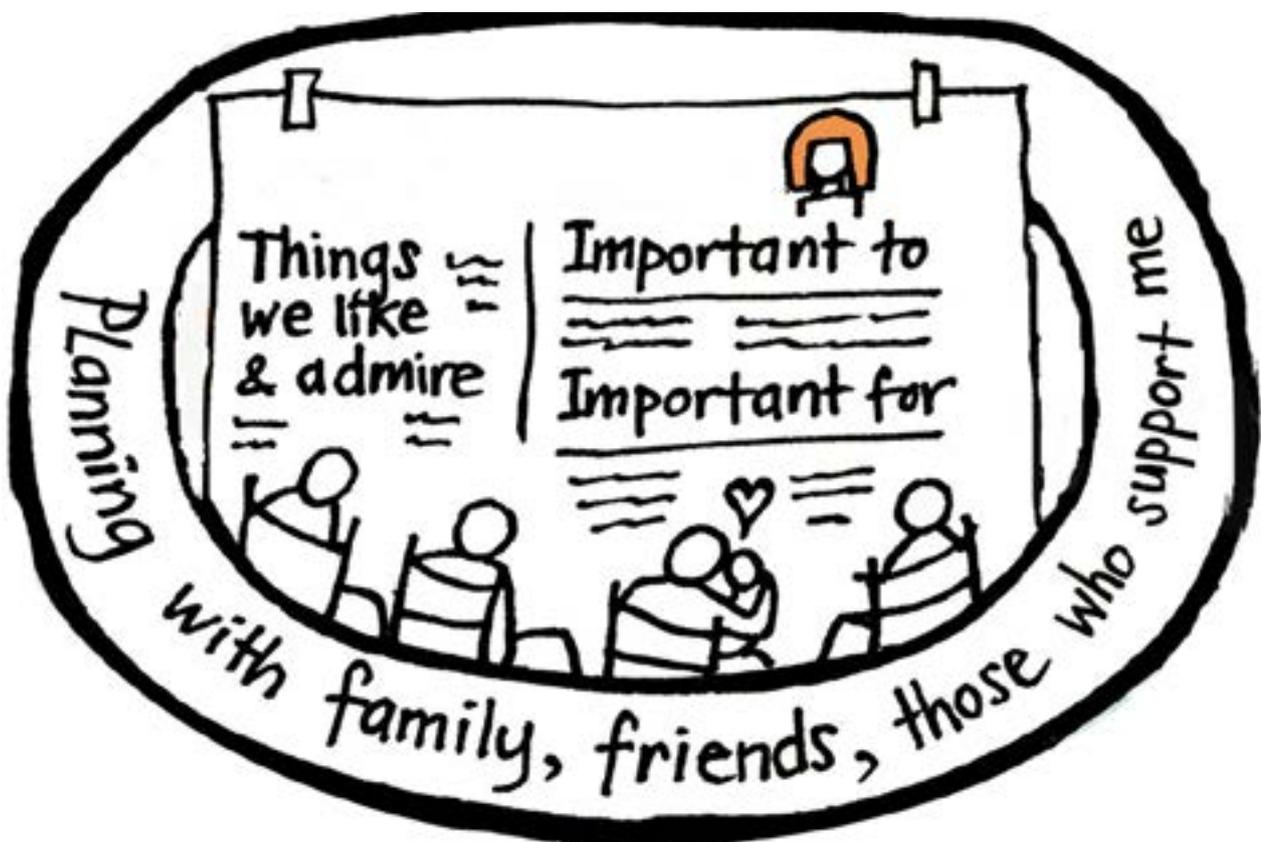


In partnership with



**making
ourselves
heard!**

PfA Factsheet: The Mental Capacity Act 2005 and Supported Decision Making



Introduction and Background

From September 2014, under Part 3 of the Children and Families Act 2014, the right to make requests and decisions applies directly to disabled young people and those with SEN over compulsory school age (the end of the academic year in which they turn 16) rather than to their parents.

This has raised a lot of questions from young people, their families, and professionals working with them, about how young people can be prepared and supported to make important decisions about their future.

Preparing for Adulthood (PfA) have worked in partnership with the Transition Information Network (TIN), the Information Advice and Support Services Network (IASSN) and Making Ourselves Heard (MOH) to develop this factsheet. We have considered the practical implications of the key principles of the Mental Capacity Act 2005 and how they link with the duties in the Children and Families Act 2014 and the Care Act.

Through working with young people we have explored how supported decision making can create positive outcomes for them as they prepare for adulthood as well as considering how they would want to be supported.

What do young people say?

As part of the development of this factsheet we ran workshops with [EPIC](#) (Equality, Participation, Influence, Change) and the Council for Disabled Children's network [Making Ourselves Heard](#).



EPIC, July 2014

You can also watch a video of a group of young people, involved in a co-production event, that captures some of their thoughts about the importance of their voice being heard, valued and the benefits to both young people and professionals of involving young people in decision making.

http://youtu.be/wtDEbeXoV5M?list=PL-J_NEPDngHyY0LstrQX0Lv0-VZ2LwjB

Young person's message to local authorities not involving young people:

"You should do it, don't be afraid, because our opinion is valuable and is knowledgeable. You will get people from all different walks of life, and all different insights and it will be a learning experience for you, not just for us but for you as well. We can learn from each other and take a wealth of experiences and a wealth of ideas. Your relationships with us will be stronger in the long run and you'll be able to deliver us what we need"

What do the Children and Families 2014 Act and the Care Act 2014 say about mental capacity and decision making?

Children and Families Act 2014

- Participating in Decision Making: local authorities **must** ensure that children, their parents and young people are involved in discussions and decisions about their individual support and about local provision.
- Specific decision making rights about Education Health and Care (EHC) plans apply to young people directly from the end of compulsory school age. These are the right to:
 - request an assessment for an EHC plan;
 - make representations about the content of their EHC plan;
 - request that a particular institution is named in their EHC plan;
 - request a personal budget for elements of their EHC plan;
 - appeal to the first-tier tribunal (SEND and Disability) about decisions concerning their EHC plan;
- The right of young people to make a decision is subject to their capacity to do so as set out in Mental Capacity Act 2005. However, if a young person is found to lack capacity the decisions relating to part 3 of the Children and Families Act 2014 will be taken on their behalf by a representative (where there is no representative appointed under the Mental Capacity Act 2005 the decision will be taken by the young person's parent).

Care Act 2014

- Local authorities **must** involve people in decisions made about them and their care and support. No matter how complex a person's needs local authorities are required to involve people, help them express their wishes and feelings, support them to weigh up options, and to help them make their own decisions.
- Local authorities **must** form a judgment about whether a person has substantial difficulty with being involved with these processes.
- The Care Act 2014 describes 4 key areas where a substantial difficulty might be found:
 - Understanding relevant information;
 - Retaining information;
 - Using or weighing the information as part of engaging;
 - Communicating their views, wishes and feelings;
- If a person is thought to have substantial difficulties as defined above and there is no person who is able to support or represent them the local authority **must** arrange for an independent advocate to support and represent that person

Children and Families Act 2014

- Local authorities, schools, colleges, health services and other agencies **should** support young people to communicate their needs and aspirations and to make decisions which are most likely to lead to good outcomes for them, involving their family where the young person is happy for this to happen. In respect of an EHC plan the final decision rests with the young person.
- Staff working directly with young people **should** be trained to support them and work in partnership with them, enabling them to participate fully in decisions about the outcomes they wish to achieve.
- Local authorities **should** ensure that young people who need support in order to make sure their views are acknowledged and valued, have access to this support.
- Young people are entitled to the same quality and level of information, advice and support as parents. Young people **must** have confidence that they are receiving confidential and impartial information, advice and support.

Care Act 2014

- Many people who qualify for an advocate under the Care Act 2014 will also qualify for an advocate under the Mental Capacity Act 2005. Where this is the case, the same advocate can provide the support to enable the person to receive seamless advocacy and not to have to repeat their story to different advocates.
- The person must agree to the appropriateness of the individual who is proposed to support them. The local authority **should** respect the person's wishes with regard to who supports them regardless of whether the person is assessed to have or lack capacity.
- If the local authority decides to appoint an independent advocate, as the person does not have friends or family who can facilitate their involvement, the local authority **should** usually still consult with those friends or family members when appropriate.
- The local authority must establish and maintain a service to provide information and advice relating to care and support to individuals and relating to support for carers.

What is the Mental Capacity Act 2005?

An overview

The Mental Capacity Act 2005 applies to everyone aged 16 or over, so parents of a young person with a disability or condition which may affect a person's capacity (such as a learning disability), should have relevant information and understand the Mental Capacity Act's potential implications for themselves and their son or daughter.

"My son has recently left school and he's in the transition stage from children to adult services. Obviously when he was a minor I made most of the decisions for him, but as he is an adult, I've had to think very carefully when I made decisions whether it is in my son's best interest and I hope I have done so."

Parent

Mental capacity is the ability to make decisions. This could be fairly small decisions like what we eat or the clothes we wear, or could be much bigger decisions, for example where we live and who we live with. Capacity is based on a single decision at a single time, so some people may have fluctuating capacity, meaning they can make a decision one day and not the next depending on their wellbeing. The Mental Capacity Act 2005 sets out what should happen when people are unable to make one or more decisions for themselves. It clarifies the roles that different people play in decision-making, including family carers, and establishes a Court of Protection which acts as the ultimate arbiter about mental capacity issues.

The parents of a young person who is unable to make a decision are likely to be involved in:

- Supporting them to make a decision
- Supporting during an assessment of their mental capacity
- Making a decision or acting on their behalf
- Being consulted when someone else makes a decision or acts on behalf of their young person
- Challenging a decision made on a relative's behalf.

There are also certain decisions that the Mental Capacity Act 2005 says can never be made on behalf of someone else, whatever their age, usually because they are about intimate personal relationships. These include:

- consenting to marriage
- consenting to sexual relationships
- voting in elections.

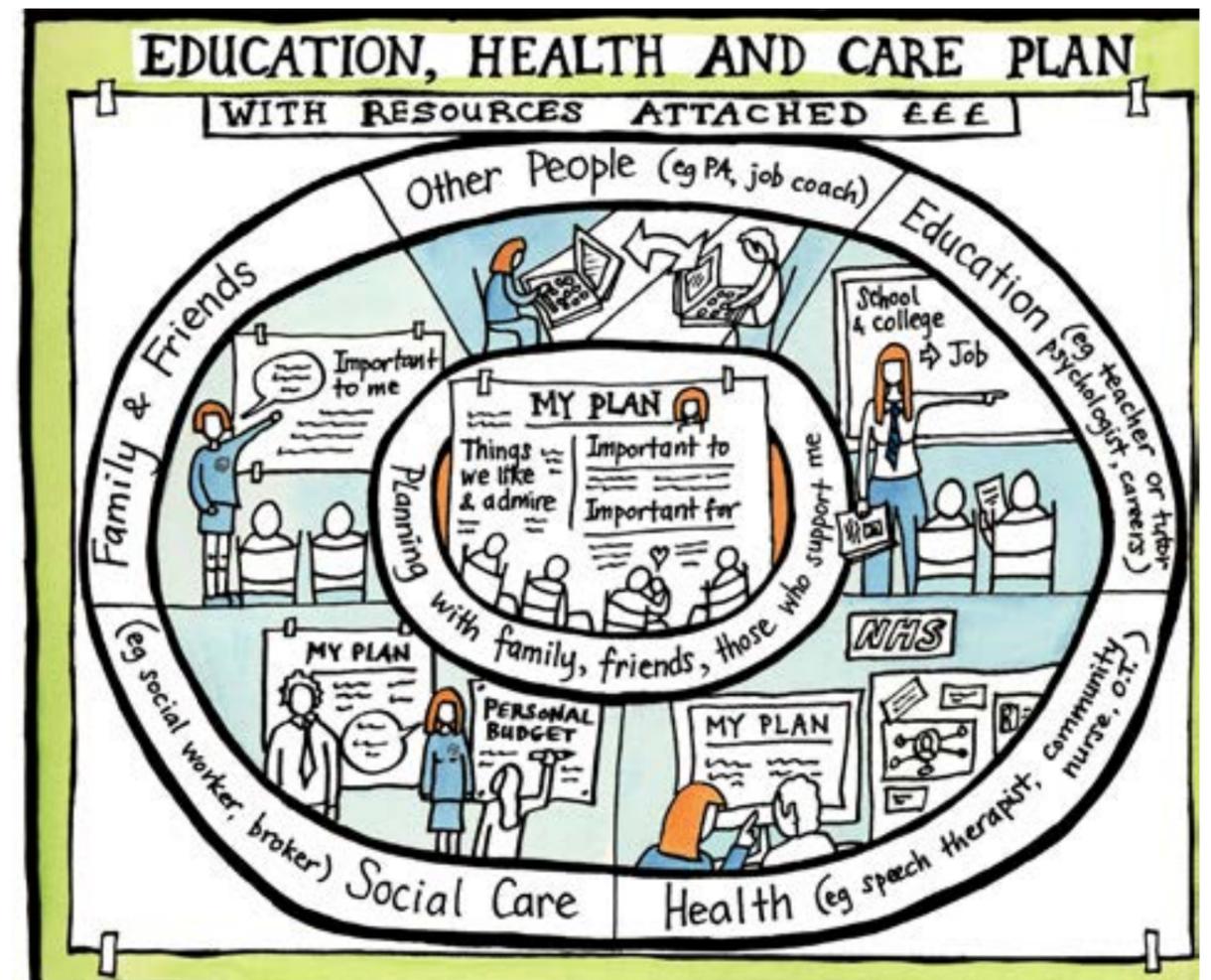
Although the Act does not allow anyone to make a decision about these matters on behalf of someone who lacks capacity to make such a decision for themselves, this does not prevent action being taken to protect a vulnerable person from abuse or exploitation.

Decision making and Education, Health and Care (EHC) plans

Specific decision making rights about EHC plans apply to young people directly from the end of compulsory school age (the end of the academic year in which they turn 16). These are the right to:

- request an assessment for an EHC plan;
- make representations about the content of their EHC plan;
- request that a particular institution is named in their EHC plan;
- request a personal budget for elements of their EHC plan;
- appeal to the first-tier tribunal (SEN and Disability) about decisions concerning their EHC plan;

The right of young people to make a decision is subject to their capacity to do so as set out in Mental Capacity Act 2005. This means that where there is disagreement about a young person's capacity to make these decisions, between professionals, parents or the young person themselves, or where there is concern that a young person lacks capacity, a mental capacity assessment should be carried out. In the case of decisions relating to an EHC plan this process will normally be led by the local authority, however to do this they will need advice from a range of people involved in a young person's care.



How the Mental Capacity Act 2005 works

Under the Mental Capacity Act 2005 the issue of capacity is decision-specific; this means that the test of someone's capacity can only be made in relation to a particular decision that needs to be made at a particular time. This is an important safeguard against blanket assessments of someone's ability to make decisions based on their disability or condition. It also recognises the fact that someone may be able to make some decisions but not others.

The Mental Capacity Act 2005 sets out five key principles which must underlie all action in determining whether someone has capacity to make a decision or not:

1. It should be assumed that everyone can make their own decisions unless it is proved otherwise

- No one should assume that a young person can't make a decision because they have SEN or disability;

2. Do not treat people as incapable of making a decision unless all practical steps have been tried to help them

- A person should have all the help and support possible to make and communicate their own decision before it is decided that they are unable to do so

A person should not be treated as lacking capacity just because they make an unwise decision

- Disabled young people and those with SEN have the right to take risks
- If they understand the consequences of the decision it is their decision to make

4. Actions or decision carried out on behalf of someone who lacks capacity must be in their best interests

- This only applies to young people who do not have capacity to make their own decision
- For a young person who has capacity their decision cannot be overturned because it is deemed to be in their best interest to do so (see principle 3)
- It is important to be clear about what is in the best interest of the young person and not be confused by what is in the best interests of those who support them

5. Actions or decisions carried out on behalf of someone who lacks capacity should limit their rights to freedom of action as little as possible.

- Before doing something to someone or making a decision on their behalf, consider whether the outcome could be achieved in a less restrictive way

Assessing capacity¹

There is a two-stage test of capacity in order to assess whether an individual has the capacity to make a particular decision. This 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.

When considering the decision-making process it's important to consider whether the young person is able to:

- understand the information relevant to the decision,
- retain that information,
- weigh that information as a part of the process of making a decision, and
- communicate his/her decision (whether by talking, using sign language or any other means).

When assessing someone's capacity to make a major or particularly complex decision, it is possible that a professional opinion may be required. This could be from a general practitioner (GP) or, if the young person has involvement from a specialist, such as a consultant psychiatrist or psychologist, it may be appropriate to contact them. In many cases a multi-agency approach is best, combining the skills and expertise of several professionals.

Professionals should never express an opinion without carrying out a proper examination and assessment of the person's capacity to make the decision.

Professional involvement might be needed if:

- the decision that needs to be made is complicated or has serious consequences
- an assessor concludes a person lacks capacity, and the person challenges the finding
- family members, carers and/or professionals disagree about a person's capacity
- the person being assessed is expressing different views to different people – they may be trying to please everyone or telling people what they think they want to hear
- somebody might challenge the person's capacity to make the decision – either at the time of the decision or later
- somebody has been accused of abusing a vulnerable adult who may lack capacity to make decisions that protect them
- a person repeatedly makes decisions that put them at risk or could result in suffering or damage.

¹ Chapter 4 of the [Mental Capacity Act 2005 Code of Practice](#).

Example scenario

Amelia has an EHC plan and is approaching the end of compulsory school age, at which point the right to make requests and decisions under the Children and Families Act 2014 apply directly to her rather than to her parents.

Under the Mental Capacity Act 2005 the local authority must assume that Amelia has capacity to make these decisions, however her parents are concerned about her capacity to make the decisions.

The fact that someone has expressed concern about her capacity is a reason for the local authority to carry out an assessment of her mental capacity to make the decisions. They will need to use a range of methods to ensure they have taken all possible steps to help and support Amelia to make and communicate her own decision before it is decided that she is unable to do so.

This could include working with Amelia's family, support staff who know her well and other professionals involved in the EHC review process to support Amelia to understand her options and communicate her views. The local authority should have a range of ways to present information, ensuring they are meeting Amelia's access needs in terms of format; environment; timings; and people present at the meeting.

The local authority need to make the final assessment of Amelia's capacity because they need the decision, however they will need the help and advice of those who know Amelia well in order to help them to do this, the personal views of these people about what they want for her must not influence the outcome of that assessment (for complex decisions, where the outcome has a significant impact on a young person's future, they may also request advice from health professionals such as a GP, psychologist or psychiatrist particularly where a young person already has input from these professionals).

As part of Amelia's assessment process the local authority carried out the following:

1. They reviewed Amelia's background through looking at previous statutory assessments and speaking to her family and established that she has a learning disability. They then needed to decide if this has an impact on her capacity to make this decision at this point in time. To do this they spoke to people who work with her at school, her family and support workers.
2. By working with a support worker who knows her well they were able to communicate and explain to Amelia what was happening.
3. They tried to help Amelia make the decision by presenting the information in a way that made it easier to understand and made sure she had accessible information about all of the options.
 - They checked her understanding after a few minutes looking for whether she was able to give a rough explanation of the information that was explained. Because Amelia does not communicate verbally they used a number of different methods (for example, observing behavior and her ability to recognise objects or pictures).
 - They avoided questions that need only a 'yes' or 'no' answer (for example, did you understand what I just said?) because they are not enough to assess the person's capacity to make a decision. Due to Amelia's communication needs there may be no alternative, in these cases they checked her response by asking questions again in a different way.
4. They allowed Amelia time to consider her options and to process the information by having 2 separate meetings; they repeated the above steps to check her understanding at the second meeting too.

Once they had done this they needed to ask the following questions:

- Does Amelia understand what decision she needs to make?
- Does she understand why she needs to make it?
- Can she understand information about the decision? Can she retain it, use it and weigh it to make the decision?

They need to consider these questions for each decision that Amelia has to make in relation to her EHC plan

It is important to remember that the fact that a person agrees with you or assents to what is proposed does not necessarily mean that they have capacity to make the decision.

In Amelia's case, after reviewing all of the evidence and considering the questions above with Amelia, her family and those who know her well, the local authority decide that she does not have capacity to make the decisions in relation to her EHC plan.

This means that, because Amelia does not have an appointed representative under the Mental Capacity Act 2005, the responsibility would revert to her parents to make a 'best interests' decision on her behalf.

Young people who lack capacity

There are a number of scenarios that may apply to young people post-16 who lack capacity for certain decisions, not just in relation to their EHC plans. Other people may need to assess their capacity to make other key decisions around preparing for adulthood, with a view to making a decision on their behalf, such as:

- A member of college staff may be weighing up whether a particular course is suitable for a student with severe learning disabilities. In such situations parents should always be closely involved both in the assessment of their capacity, and the decision that is made in their best interests.
- Parents may need to make a decision in their young person's best interests, or may be consulted by someone else about their best interests about where a young person should live.
- Parents may seek authority to make certain types of decision for their young person once they have turned 16 if they cannot make these themselves. Many parent carers become a welfare benefits appointee or a deputy to manage their son's or daughter's finances.

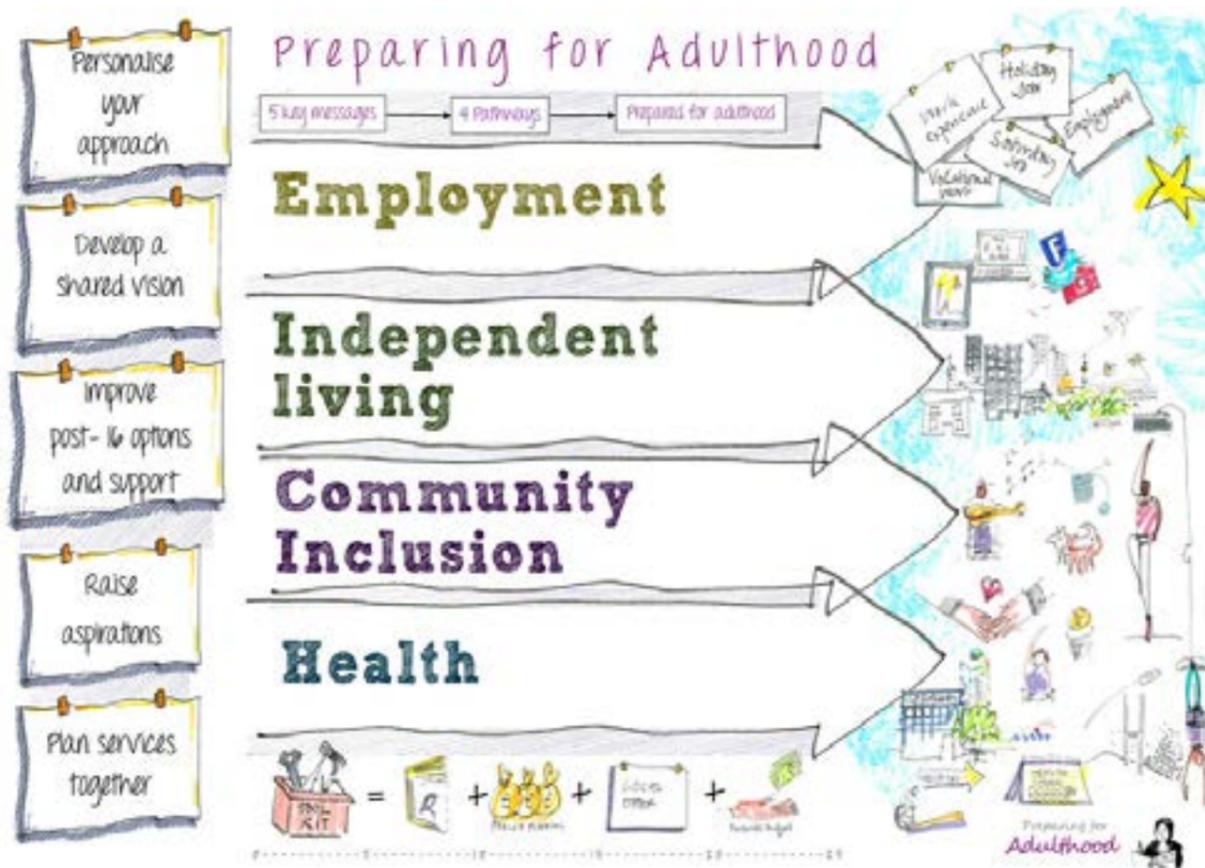
Parents and professionals must always support a young person to be involved as a much as possible in a decision made on their behalf, even if they do not have the capacity to make it themselves.

Making decisions in someone's best interests

If someone is assessed as being unable to make a decision themselves, another person may make the decision or act in their 'best interests'. In these situations the person who must lead the 'best interests' process is the person who requires the decision to be made; for example a doctor who requires consent before carrying out treatment. As far as possible the person must be involved in the process and those with an interest in the person's welfare should be consulted so that all the factors relevant to the decision can be weighed up, including the known wishes and feelings of the person, and any beliefs or values they have that might influence the decision. The decision-maker should be clear about their decisions and the reasons for arriving at it, and in the case of more serious decisions the process should be recorded in writing.

The Mental Capacity Act 2005 Code of Practice (5.13) sets out a [Best Interests checklist](#) to support this process.

When considering a young person's 'best interests' it is important to keep in mind the preparing for adulthood outcomes: employment; independent living; good health; and friends, relationships and community participation.



http://www.bestinterests.org.uk/case_studies/

Mental Capacity and the Care Act 2014

The Care Act 2014 makes explicit reference to situations where an adult may be unable to make decisions about his or her care and support, but also applies the principles of the Mental Capacity Act 2005 in setting out the duties of local authorities.

For example, the Care Act 2014 says that a local authority, in carrying out a needs assessment, must involve:

- the adult,
- any carer that the adult has, and
- any person whom the adult asks the authority to involve or, where the adult lacks capacity to ask the authority to do that, any person who appears to the authority to be interested in the adult's welfare.

Local authorities should ensure that information about the assessment process is available in a format that will help young people to be involved, that appropriate forms of communication are used and that the help and advice of parents and carers is sought at all times. Young people may be able to express feelings, wishes and preferences relating to the decision even if they are unable to play a decisive role in the outcome.

Parents must be consulted about any proposed care plan drawn up for their young person and the local authority must be able to show how parent's views, and those of the young person, have been taken into account in the decision-making process.

The Care Act 2014 establishes Personal Budgets as the mechanism for funding the care and support plan for eligible adults and clarifies their right to request a direct payment to meet some or all of their care and support needs. It also reaffirms the right of people who lack capacity to request a direct payment, to nevertheless gain the benefits of this arrangement, where it is established to be in their best interests and can be managed on their behalf by someone else.

What is Supported Decision Making?

The SEND Code of Practice: 0 to 25 years states:

“As young people develop, and increasingly form their own views, they should be involved more and more closely in decisions about their own future. After compulsory school age (the end of the academic year in which they turn 16) the right to make requests and decisions under the Children and Families Act 2014 applies to them directly, rather than to their parents. Parents, or other family members, can continue to support young people in making decisions, or act on their behalf, provided that the young person is happy for them to do so, and it is likely that parents will remain closely involved in the great majority of cases.”

In order to effectively support someone to be involved in decision-making you have to know and understand them and appreciate their individual perspective on their life. Embedding personalisation and person-centred approaches into all interactions with children and young people is key to ensuring that young people are prepared and able to participate, and are supported to make informed decisions.

It is vital to start preparing young people for decision making early. From a young age most children are making small decisions, such as what to have for breakfast or what to wear, and gradually building their confidence and taking more choice and control over their lives. This should be no different for disabled children and young people.

“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

The Mental Capacity Act 2005 clearly promotes the assumption that a person has capacity, and every effort should be made to support the person in making a decision.

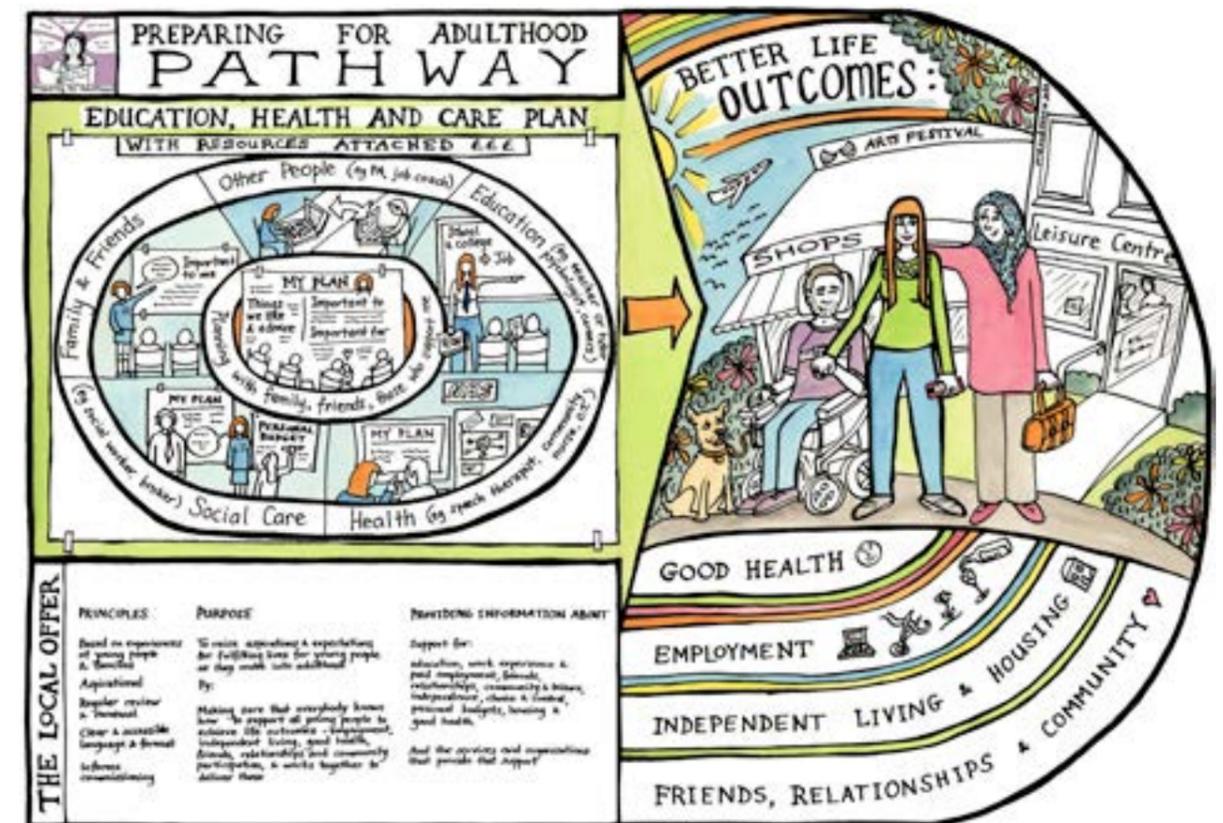
There are also clear requirements across both the Children and Families Act 2014 and the Care Act that children and young people are involved in:

- Person-centred, outcome focused assessment and planning;
- Developing the Local Offer and developing community services;
- Informing the joint commissioning priorities across education, health and care;

What does it mean in practice?

Local authorities must ensure that:

- Young people are involved in developing the Local Offer¹
- Young people are actively involved in the EHC planning process and are enabled to participate fully in decisions about the outcomes they wish to achieve.²
- that the focus is on positive life outcomes for young people, using person-centred approaches, enabling them to be as independent as possible.³
- Young people receive confidential and impartial information, advice and support.⁴
- Information needs to be accessible and available in a range of formats including easy read;
- IAS should be available face-to-face for young people that want or need this;
- Information needs to be age appropriate;



¹ SE7 have held a young person's consultation event on the SEND Local Offer, you can download the report here for more information: http://www.preparingforadulthood.org.uk/media/332384/yppeg_consultation_event_30_11_13.pdf

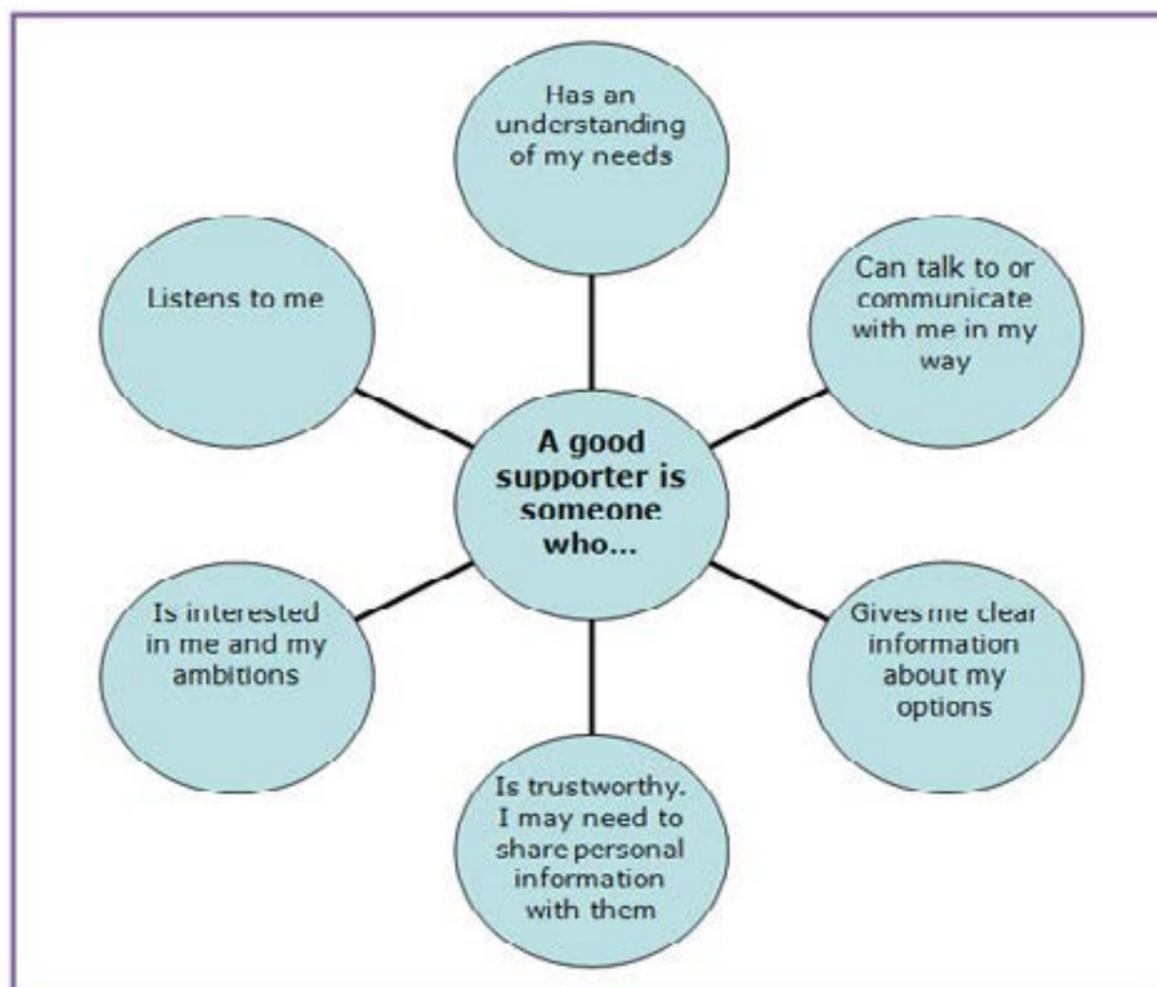
² Oakfield school and college in Wigan have recently worked with PFA to hold a planning live day with their post-16 students, you can read more here: www.preparingforadulthood.org.uk/resources/pfa-resources

³ The Council for Disabled Children have developed a tool, [The EHC Outcomes Pyramid](#), to help professionals and parents to identify outcomes for children and young people with SEN.

⁴ For more information visit the [Information, Advice and Support Services Network](#)

Local authorities **should** ensure that:

- Staff working directly with young people are trained to support them.
- Young people who need support from an independent skilled supporter, in order to make sure their views are acknowledged and valued, have access to this support.



PfA & EPIC workshop - July 2014

What helps young people prepare for choice, control and decision-making?

The VIPER (Voice, Inclusion, Participation, Empowerment, Research) project looked at disabled children and young people's participation in decision making, specifically around service development and delivery, however many of the findings are transferable to other individual decisions too.

A few of their key recommendations were:

- **Assume young people can be involved in decision making** – misconceptions and low aspirations about disabled young people's ability to be involved in decision making leads to parents and professionals making decisions without trying to involve young people;
- **Have a positive attitude to working with disabled young people** – the research suggests that due to a perception that disabled young people are too hard to work with many of them are excluded from decision making. This was particularly the case for young people in care, those from minority ethnic groups and those with more significant access needs;
- **Good accessibility** – Many young people are unable to participate in decision making because their basic access requirements are not being met. This could be communication needs, room size, not enough advance notice of meetings, not enough or inaccessible information;

You can download the full report from the VIPER project <http://vipercouncilfordisabledchildren.org.uk/media/7834/hear-us-out.pdf>

It is vital that children and young people are supported, by their families and the professionals working with them, to be as involved as possible in decisions from a young age. This could be simple decisions like what to eat for breakfast or what colour clothes to wear but these small choices help young people to build the skills that they need to process information, consider options and make more complicated decisions as they get older.

For disabled young people to be fully involved in decision-making and to have choice and control over their lives those who support them, including professionals, their families and friends, should:

- Use person-centred approaches that focus on strengths and abilities
- Listen to young people about who they want involved
- Listen and understand how they want and need to communicate
- Include people that know the young person well
- Make sure the environment allows young people to be involved - be flexible and give them choice over the venues and timings for meetings
- Provide information in a range of accessible formats
- Give young people time to process information and think about their options

Resources

Statutory Guidance

SEND Code of practice: 0 to 25 years

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

Mental Capacity Act 2005 Code of practice

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

Practical resources

Paradigm - Supported Decision Making: A Guide for Supporters

This guide offers people best practice techniques and tools that may be useful when supporting others with supported decision making/

[http://www.helensandersonassociates.co.uk/media/43801/supported%20decision%20making%20\(final%20online%20version\)%20\(2\).pdf](http://www.helensandersonassociates.co.uk/media/43801/supported%20decision%20making%20(final%20online%20version)%20(2).pdf)

Viper report - Hear us out

http://www.councilfordisabledchildren.org.uk/media/284859/hear_us_out_.pdf

In Control - Supported Decision Making

This toolkit is about practical approaches in decision making.

http://www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/london/Supported_Decision_Making.pdf

BILD - Brief guide to the Mental Capacity Act 2005: Implications for people with learning disabilities

<http://www.scie.org.uk/publications/mca/files/bild-mca.pdf?res=true>

SCIE - Care Act 2014: Commissioning Independent Advocacy

<http://www.scie.org.uk/care-act-2014/advocacy-services/commissioning-independent-advocacy/>

Resources for Families

Using the Mental Capacity Act

HFT Family Carer Support Service has produced Mental Capacity Act resource for family carers comprising films and written information on different aspects of mental capacity, including one about transitions.

<http://www.hft.org.uk/Supporting-people/Family-carers/Resources/Using-the-Mental-Capacity-Act/>

Special Educational Needs and Disabilities: A guide for parents and carers

<https://www.gov.uk/government/publications/send-guide-for-parents-and-carers>

Mental Capacity Act 5 Key principles video

<http://youtu.be/wci99OawH8U>

Useful websites

Preparing for Adulthood

<http://preparingforadulthood.org.uk/>

Transition Information Network

<http://transitioninfonet.org.uk>

The Information, Advice and Support Services Network (IASS Network)

<http://www.iassnetwork.org.uk/>

Making Ourselves Heard

<http://www.councilfordisabledchildren.org.uk/what-we-do/networks-campaigning/making-ourselves-heard>

Council for Disabled Children

<http://councilfordisabledchildren.org.uk/>

National Development Team for Inclusion (NDTi)

<http://www.ndti.org.uk/>

British Institute of Learning Disabilities (BILD)

<http://www.bild.org.uk/>

Paradigm

<http://www.paradigm-uk.org/>

Personalising Education

<http://www.personalisingeducation.org/>

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Web: www.preparingforadulthood.org.uk

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