

**Decision Making  
by Your Child with  
Special Educational Needs  
A booklet for  
Parents & Carers**

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## Introduction

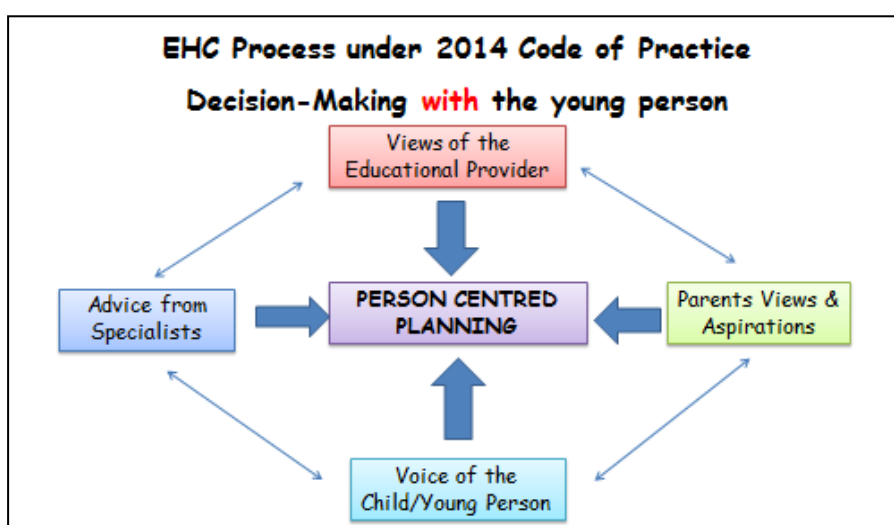
From September 2014 the new procedures for children with Special Educational Needs and Disability (SEN and Disability) 0-25 years will be in force.

The increasing importance given to the views of the child, have now been established in law. This booklet sets out to simplify and explain this process, so that you can fully support your child as he/she grows into adulthood.

### How do expectations change over time? (see appendix 1)

When your child is very young, they are unlikely to be able to express their views about their SEN and Disability and you will need to represent his/her needs and aspirations.

As your child gets older, then his/her voice needs to be heard and you and the educational providers and care staff will need to explore the best ways to get these views expressed and listened to at planning meetings and discussions about them.



The importance of the child's views (and the school's) increase as they get older, being the time when they are starting to understand the implications of what is happening to them as equal partners.

By your own or the child's looking at 10 years ahead and the process and the

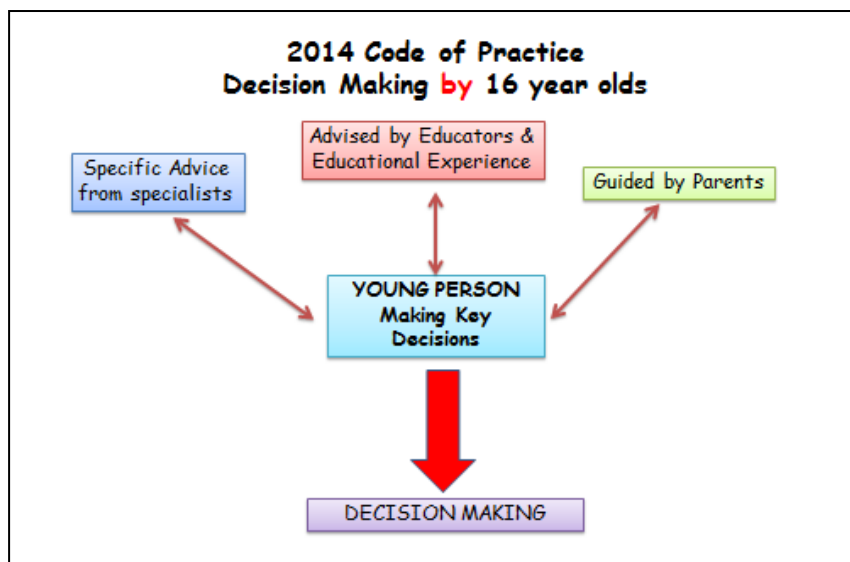
By encouraging and supporting your child to express themselves more clearly and ensuring what they say is being taken seriously, by the age of 16 legally their views are given greater weight above your or anyone else's views.

### What can they make decisions about?

Initially their views will be about their condition or SEN, what is happening to their education, what the purpose is of any support and where and how they might best be educated.

By the age of 16 they will be able to:

- Request a statutory assessment for an Education, Health and Care Plan (EHC).
- Challenge the content of such a plan.
- Specify a school/centre of their choice.
- Request a personal budget for their special needs.
- Appeal to a Special Tribunal (SEN and Disability) if they are not happy with the content of their EHC.



### **What if they find making decisions very difficult?**

If the child is developmentally very young, has learning difficulties, a disability or a long-term illness which affects their ability to think about a decision, then every effort should be made to help them arrive at their own independent opinion.

This also applies to a child or young person who has suffered an emotional trauma (such as an accident or brain injury or has lost someone close to them).

This help could include:

- Using an independent person to support them *e.g. a relative, specialist or family support worker*
- Adapting the information so that they can understand *e.g. simplifying or breaking the task down*
- Use different communication aids like they do in school *e.g. video, pictures or specialist systems*
- Give them practical examples to simplify the process *e.g. taking them step by step through the process*
- Working on their understanding over a period of time *e.g. slowly working over days or weeks to arrive at a decision*

### **What if they are still unable to understand?**

This is referred to as “lacking mental capacity” although it must not be assumed that they lack capacity just because they have a particular condition such as Down’s Syndrome, or a fear that they will make an unwise decision.

Although it is assumed that everyone (with the right sort of support/guidance) will be capable, there will always be a minority of young people who will not have the capacity to make important decisions about themselves.

If you are not clear about this then you may ask for the advice of a psychologist, psychiatrist, social worker or a speech and language therapist.

When it is clear that the person lacks capacity then you must try to make decisions on their behalf that:

- Are in their personal interest (not your interest or anyone else's).
- Ensure that their personal needs for education, stimulation, independence and their personal rights are being met.

### **How will we know that the person can make a decision?** (see appendix 2)

Anyone working with or supporting a young person with SEN or a disability may have a “reasonable belief” that he/she may not “have the capacity to make this decision at the present time” and when they have the opportunity of making a particular decision:

- Do they understand the consequences of the decision?
- Do they understand the consequences of an alternative decision?
- Can they retain the information long enough to make the decision?
- Can they use the information in making this decision?
- Can they communicate the decision to other people?

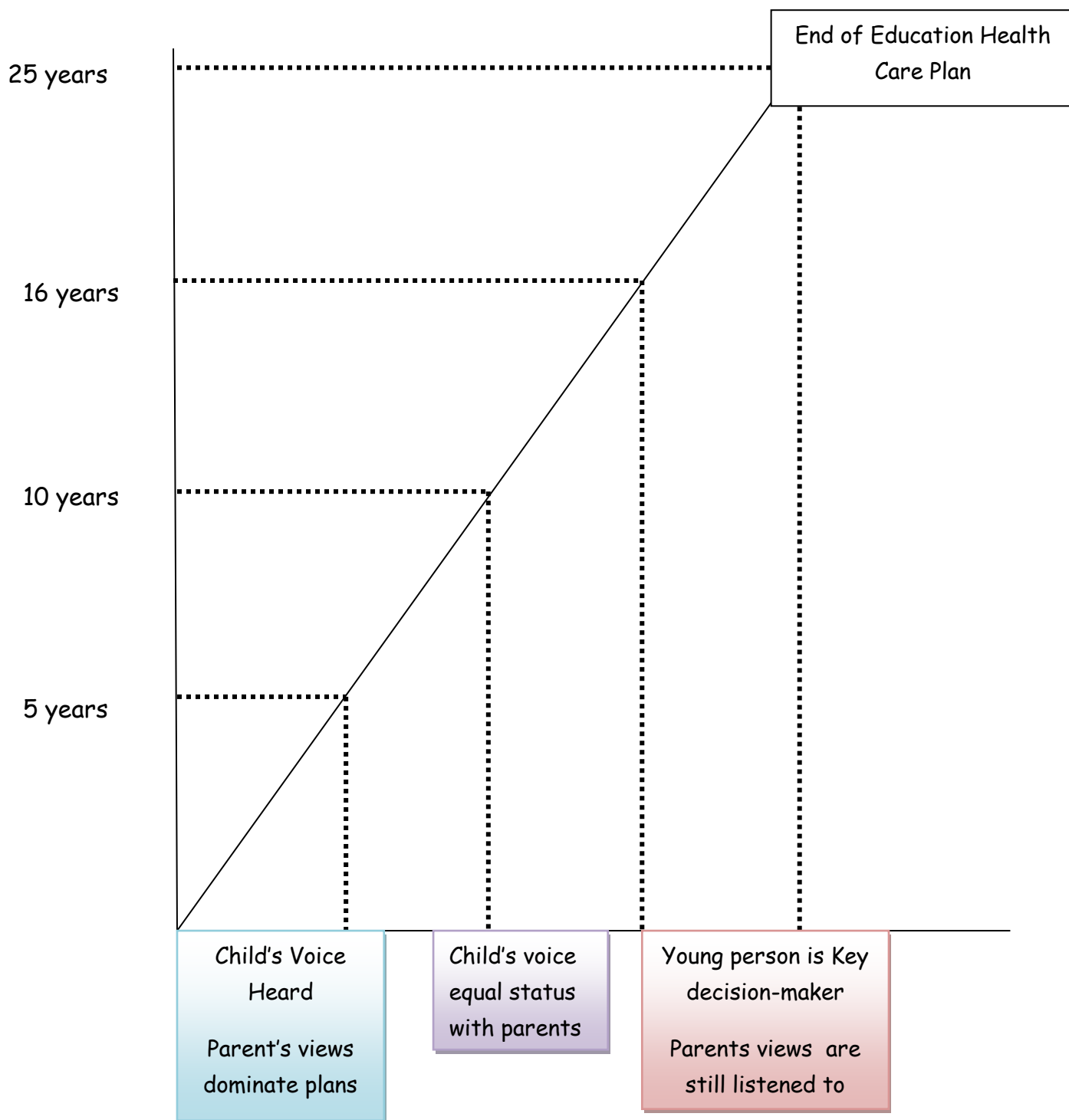
### **Some examples to illustrate how vulnerable young people have been supported to develop capacity in spite of concerns expressed by their carers**

1. An 8 year child with Downs Syndrome and delayed language worked with his support assistant for weeks before his planning meeting and he produced a series of pictures to use at his planning meeting, about his aspirations and wishes (about participation in social groups in school, desires to join a scout group, desire for some freedom when shopping, etc.)
2. An 18 year old with a specific language difficulty developed a written description of his condition and had a series of scripts which he learned to take to university interviews and was accepted onto a degree course
3. A student, with complex communication needs, had a simplified question and answer script and used a signing board to communicate her answers and was able to participate fully at her planning meetings.
4. A traumatised, emotionally disturbed looked after child worked carefully with an independent mentor over a number of weeks to decide upon access contact with her birth parents.

## **What can we do as parents/carers to help our child make good decisions as a young adult?**

1. However disabled your child is , make the skill of personal decision-making this one of your main expectations for him/her, and help develop this gradually as he/she matures.
2. Start from a very early age by expecting him/her to make choices, initially about simple things like foods, clothes, activities etc
3. Make the choices “real” so that your child has to “live with the consequences of an unwise decision”
4. Respect their choices as “different from your own” and not just “right or wrong”.
5. If they(or you) find it difficult to express a different opinion to yours, ask someone else to mediate (such as an older sibling, grandparent or family friend)
6. From an early age find out what their views are about school, teaching approaches and the support they are getting and help them to express these in planning meetings (e.g. using videos, drawing, prepared scripts etc)
7. Tell him/her that by about 10 years old (year 6) his/her opinions will have the same value as everyone else’s (make sure that these views are listened to and recorded)
8. As a teenager give him/her lots of opportunity to make decisions and lots of time to discuss the “sensible “and the “silly” ones and what the consequences are.
9. As the decisions become more complex (such as independent living, careers, social participation etc) give the young person as much time and information as you can and help him/her arrive at their own decisions as a 16 year old
10. When they make “unwise” decisions give them time and opportunity to change their minds but still respect their ability to make decisions
11. Even when they really lack capacity give them some choices to make and ensure that any decision made for them is in their best interests.
12. It’s really hard “letting your child grow up to be an adult” , especially when they are particularly vulnerable, but “small steps are the way to climb the mountain”

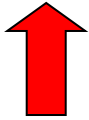
## The Growing Importance Of The Voice Of The Child/Young Person With SEN



# DOES THIS PERSON HAVE THE CAPACITY TO MAKE THIS DECISION?

## PART ONE

YES



Does the person have the capacity to make this decision at the present time?

The person's views must be taken into account even when this decision is unwise?

- Does he/she understand the consequences of the decision?
- Does he/she understand the consequences of (an) alternative decision(s)?
- Can he/she retain the information long enough to decide?
- Can he/she use the information in making the decision?
- Can they communicate the decision to other people?



## PART TWO

NO



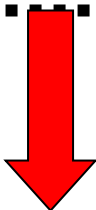
Does the person have the capacity to make this decision at the present time?

What additional support/aid can be given to facilitate the person's capacity to make a decision?

- More relevant information?
- Communication aids and different modes of expression?
- Adult mentors or mediators?
- Practical experiences to facilitate understanding?
- Emotional support and counselling?
- Time and space to decide?



YES



NO



## PART THREE

Decisions must be made in the best interest of the person and all future decision must also pass the capacity test