Involving young people in decisions

It's easy for parents to go on making decisions for disabled young people as they grow into adulthood, especially if it seems hard to be sure what their views are, or be confident that they are able to make informed choices. But, whatever your fears, young people themselves are the ones most likely to know what they like and don't like and what kind of life they might want in future. What's more, the law says that once your child is 16 they have the right to make their own decisions unless they lack the mental capacity to do so, so it makes sense to help them practise making decisions as early as possible.

If your son or daughter has an Education, Health and Care (EHC) Plan, you can expect them to be included and involved in making decisions about their future from their annual review in Year 9 onwards. This is called ‘transition planning’ and it will focus on their strengths, interests and aspirations and help identify their future needs around education, health, housing, relationships and work. If you haven't already started to involve your young person in decision making, the sooner you can start the better. Take a look at our companion fact sheet, Preparing for adulthood, for more ideas on involving them in the transition process.

This fact sheet gives you advice on how to build their decision making skills and put young people's wishes at the centre of planning for their future – this is sometimes called using a ‘person centred’ approach to planning.

Prepare the foundations for decision making

Give disabled young people the belief that they and their views matter. Don't just think it, say it out loud, often.

Encourage young people to take chances and try new things. Whatever it is they are considering, it's hard to express a preference about things they haven't tried.

Take time to think about important matters. Young people rarely make decisions they are happy with if they feel rushed or haven't been able to give their whole attention to the problem.

Unpack worries. Give young people strategies to deal with their worries and build in safeguards to deal with yours. Whether real or imagined, worries need to be taken seriously. They get in the way of trying new things.

Build their decision making skills

Talk through practical things or think aloud to help a young person understand how to go about problem solving and reasoning.

Avoid overwhelming them with too many choices. You could discard or reduce alternatives quickly by agreeing what's practical or by grouping options by an important common factor. And take care not to offer an illusion of choice, when really there is none.

Build in opportunities to make everyday choices about things like clothes and food, as it’s difficult to make important decisions if you haven't had lots of practice making smaller ones.

Make decisions as a family. It can help a young person learn that it's fair for everyone to have a
chance to say what they think, that it's okay to have different ideas, to change your mind after hearing
what others think and that sometimes we go with a ‘majority decision.’

**Think little and often.** Sometimes it’s more productive to do 5 or 10 minutes thinking a day
over several weeks rather than a couple of longer sessions.

**Be truly prepared to accept their choice** – it may not be the one you hoped for.

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**Preparing for meetings**

**Information is power.** Young people need to know about their rights, the options that are
available to them. They need to know what the meeting is about, who will be there, and the sorts of
things they can say. If you aren't sure yourself, you need to find out.

**Encourage your child to use professional advocacy services** if it makes sense for them to access
independent support at a meeting. See the ‘Ask about’ section at the end of this fact sheet for local
advocacy services.

**Encourage a young person to record their views in a way that suits them.** Think about using
photographs, drawings, video and audio recordings as well as observation to ‘catch and record’ their
wishes and feelings. Questionnaires in word, sign or symbol can help many young people organise
their ideas and contribute to their meetings.

**Check the practicalities of the meeting work for your young person’s needs:**

- Is the venue accessible and familiar and the meeting at a time when the young person is best
  able to contribute?
- Will the young person be present for all or part of the meeting, and which part? Agree what will
  happen if they want to leave the meeting or take a break
- Would the young person like the meeting taped or someone nominated to take notes on their
  behalf?

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**At the meeting**

**Make sure it’s only one question at a time.** Encourage open questions, so you get more than a
‘yes’ or ‘no’ answer. Reflect back what you think the young person is telling you, to check you have
understood them clearly. Avoid making any assumptions about what's important to them.

**Take care the young person's decisions aren't ‘cued’;** that options aren't limited for anyone
else's convenience, or presented in a way that's likely to lead them to make a choice just to please
others. Remember it's not just what is said, but how it's said, that matters.

**If it's not easy to be sure what the young person means, acknowledge that you've got lost and
start again.** Be patient, and resist the urge to rush and fill silences. Let them know you won’t
be cross whatever they wish to say.

**Make sure copies of the young person’s views are circulated** to everyone attending meeting,
along with your advices and those of others.

**Agree a ‘code of conduct’ for participants.** This might include:

- encouraging the young person to choose where they sit
- reminding everyone whose meeting it is (the young person's) and what needs to be discussed
- introducing the young person to anyone they don't know well and explaining why they are there
INVOLVING YOUNG PEOPLE

- checking if there is anyone the young person wishes to be present for just part of the meeting
- asking the young person who it is okay to ask for help if someone doesn't understand their communication - it’s hopeless if everyone tries to help!
- agreeing not to challenge anything the young person ‘says’ or interrupt or finish their sentence
- checking back that they feel their question has been answered, and if not, letting them have another go
- recapping all the things everyone agrees to do, checking the young person has fully understood what has been said or agreed, by asking them to say what they think is going to happen

Ask about

- **SENDIASS** - Amaze provides Information, Advice and Support (IAS) to children and young people with SEND in East Sussex and their parent carers. Our helpline advisers can talk to you or your son or daughter on any issue related to their SEN or disability and SENDIASS advisers may be able to give you more targeted support. Call 01273 772289, email sendiass@amazesussex.org.uk or visit amazesussex.org.uk
- **Advocacy services** - can help disabled children and young people be heard. POHwER East Sussex (0300 456 2370 or pohwer.net/east-sussex) or Speak Out! (0300 303 9649 or changegrowlive.org/young-people/speak-out) provide support for young people with SEND or looked after children.
- **Youth Employability Service** - has Skills and Employability advisers who offer individual support to young people with transition planning. They coordinate transition plans for young adults and should check that a young person isn't missing out on benefits, entitlements to assessments and services from adult social care, health, housing and career options (01424 722045 or facebook.com/YESEastsussex/)

Further information

- **Starting to prepare for adulthood fact sheet** - Amaze produces a companion fact sheet called ‘Starting to prepare for adulthood’. This is all about transition planning. Visit amazesussex.org.uk/resources/publications/fact-sheets
- **East Sussex’s Local Offer** - The council's comprehensive online listing of all services for children and young people with SEND in East Sussex includes lots of information about services for young people. See eastsussexgov.uk/localoffer
- **Foundation for people with learning disabilities** - They provide lots of information and resources relating to transition and person centred planning. Visit learningdisabilities.org.uk/help-information/learning-disability-a-z/t/transition