

INVOLVING YOUNG PEOPLE

This fact sheet has been written by parent carers for parent carers.



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.





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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.'

'Little and often' – sometimes it's more productive to spend five or ten minutes thinking about something 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.

Preparing for meetings

Information is power. Young people need to know about their rights and 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?

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 the meeting, along with those from you and any professionals involved.





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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
- 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

- **Choice Forum** – discussion forum for people with learning disabilities and their families. Go to: www.choiceforum.org.uk.
- **Reaching Families** – provides training, information & other fact sheets related to this topic. See especially our workshops on *Making Sense of Adult Life*. We also offer benefits advice, peer support, a Facebook group & handbook (see below) for parent carers of children & young people with SEND in West Sussex. See: www.reachingfamilies.org.uk.
- **West Sussex Advocacy Service** – can help disabled children and young people who have a social worker. Advocates can go to meetings with a young person, help them to make a complaint or get legal advice. Call: **0330 222 8686**, email AdvocacyService@westsussex.gov.uk, or go to: www.westsussex.gov.uk/education-children-and-families/your-space/support/advocacy.
- **West Sussex SEND Information, Advice and Support (SENDIAS) Service** – contact them for independent advice and support about children & young people's special educational needs and/or disabilities. They also have Young People Advisers, who can support young people up to the age of 25 to help them to think through their options. Go to: <https://westsussexsendias.org.uk>, **0330 222 8555**, or email: send.ias@westsussex.gov.uk (parent carers) or: cyp.sendias@westsussex.gov.uk (children and young people).

Further information and useful links

- ***Making Sense of it All: From Birth to Adulthood*** – Reaching Families' handbook for parent carers of children and young people with SEND in West Sussex. This provides essential information on money matters, including claiming DLA and PIP, as well as social care, health, leisure, travel, education and employment. Go to: www.reachingfamilies.org.uk/guides.html.
- **National Development Team for Inclusion:** – has a range of tools & resources about preparing for adulthood & involving your young person. Go to: www.ndti.org.uk/resources/preparing-for-adulthood-all-tools-resources.
- **West Sussex Local Offer** – go to: <https://westsussex.local-offer.org> for local services, support and details of Short Breaks providers for children & young people aged 0 - 25 years with SEND.

