

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 young person 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, *Starting to prepare 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.'

Do it 'little and often'. Sometimes it's more productive to do 5 or 10 minutes a day 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, 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 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 meeting, along with your advice and those of others. These should all be sent in advance so there is time to think about them before the meeting.

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

- **Amaze SENDIASS** (Special Educational Needs and Disability Information, Advice and Support Service) offers impartial, confidential advice on anything to do with special educational needs and disabilities for 0 to 25 year olds. Parents, carers, children and young people under 25 with SEND living in Brighton & Hove or East Sussex can use the service. Email sendiass@amazesussex.org.uk, call 01273 772289 or visit our website at <https://amazesussex.org.uk>
- **Amazing Futures peer support and activity groups** - Regular social and support groups for young people with SEND at various venues across Brighton & Hove and East Sussex. Visit our Amazing Futures website at <https://amazingfuturesussex.org.uk>. Get details of all upcoming groups at <https://amazesussex.org.uk/events>
- **Amazing Futures Careers** (Brighton & Hove only) can meet young people with SEND to look at all the options available after 16 for work, training and education. Call Dara on 07485 345903 or email afcareners@amazesussex.org.uk
- **Advocacy services** can help disabled children and young people be heard. **Brighton & Hove's Youth Advocacy Project** offers advocacy for children and young people with a disability. Call 0800 0524 280 or go to: www.bhyap.org.uk/your-zone/what-advocacy. **Brighton & Hove Speak Out** offers advocacy for young people aged 17+ with a learning disability Call 01273 421921 or visit their website: www.bhspeakout.org.uk. **Asphaleia Care** offer advocacy to under 18s who have an East Sussex County Council social worker. Call 01323 324010 or visit their website at <https://www.asphaleia.co.uk/ivandadvocacy>. **SWAN (South East Advocacy Network)** provide advocacy services for children, young people and adults in East Sussex. Call 0800 862 0995, email eastsussex@swanadvocacy.org.uk or visit <https://swanadvocacy.org.uk/services-near-you/east-sussex>.
- **Youth Employability Services** have specialist advisers who can support young people with planning the transition to adulthood. **Brighton & Hove Youth Employability Service** (01273 294247 or www.facebook.com/yesbrightonhove). **East Sussex Youth Employability Service** (01323 368390 or <https://www.cxx.org/resources/east-sussex-ehcp-resources>)

Further information

- **Amaze's fact sheets on *Meetings and paperwork* and *Preparing for adulthood***. Download from <https://amazesussex.org.uk/resources/fact-sheets>
- **Brighton & Hove City Council's Easy Read Information Hub** - easy read information about council services <https://www.brighton-hove.gov.uk/easy-read-information>
- **British Institute of Learning Disabilities (BILD)** - information and resources for families and easy read guides for people with learning disabilities. Go to: www.bild.org.uk.



INVOLVING YOUNG PEOPLE



- **Choice Forum** – discussion forum for people with learning disabilities and their families. Go to: www.choiceforum.org.uk.
- **Foundation for People with Learning Disabilities** – part of the Mental Health Foundation, it provides lots of information and resources relating to transition and person-centred planning. Visit <https://www.learningdisabilities.org.uk/learning-disabilities/a-to-z/t/transition>
- **Local Offers:** each local authority has an online directory of all the services that are available for children and young people with SEND and their families locally. See <https://eastsussexgov.uk/localoffer> or <https://www.brighton-hove.gov.uk/special-educational-needs-and-disabilities>
- **Scope online community** - forum for people with disabilities and their parents and carers to connect, share stories and get advice <https://forum.scope.org.uk/>
- **Transition Information Network** - a specialist network of the Council for Disabled Children that provides 'best practice' information and resources about transition. Also publish My Future Choices magazine for disabled young people, families and professionals. <https://councilfordisabledchildren.org.uk/about-us-0/networks/transition-information-network>

