

CHAPTER 2

Involving your child



We made important decisions for our children when they were young, and for many of us it felt safe and reassuring to go on doing so even as they became young adults. We are used to looking out for their best interests and trying to ensure their needs are met: after all, often we only got additional support or specialist services through careful negotiation and persistence. Getting things right can feel like a huge responsibility and now they're moving into adulthood, it doesn't feel any different. So it's no surprise parents may feel nervous about involving young people in decision making.

However, young people are the ones who know what they like and don't like - although we may find it hard to disentangle our

own hopes from what they want for themselves. Solutions that take their wishes and feelings into account are more likely to work. And in our experience, a young person's views are likely to be given greater weight if they communicate directly with those involved in the decision making process. But they will need your support.

Young people have a huge variation in their ability to make decisions, but the information in this chapter is relevant to all families, including those who feel their teenager has a limited ability to express their views. Most young people can show both positive and negative preferences to a person, a place or an activity and this ability can be invaluable when making decisions. Some young people use forms of communication other than speech to express themselves, but for ease, we've used terms like 'she tells us' or 'he says' to cover the whole range of communication.

In this chapter, we suggest ways you can involve young people and how you can help them learn about decision making. We look at how you can make sure your child's voice is heard in transition planning. And we provide information on some of the rights you and your child have in the eyes of the law.

CHOICES FOR OUR CHILDREN

Sometimes the thing that gets in the way of us encouraging a young person to 'have a say' is that it seems impossible to be sure what their views are. We worry that they will be unable to think through what is for the best, or will ask for a service that can't be delivered and we will be left to manage their disappointment. Worst of all, we fear they might make a choice they regret.

Often society doesn't give the views of children and young people serious recognition. This is especially true for disabled

children who can get the message that other people have more important things to say and the world is full of people who are better than they are.

'You get talked about by everyone, "where shall we sit him, what time does he go to bed" in front of you. You really believe you aren't as much of a person as everyone else. You'd never think of having a say.' (Jack 16)

The balance between involving your child and fulfilling your role as a parent and protecting their best interests can seem a difficult one. But at 16, they'll legally have the right to make their own decisions, according to their 'mental capacity' (see page 38) and at 18 they're legally adults. It's part of our job as parents to help them prepare for this during their teens. Worries about their vulnerability as adults can stop us encouraging young people to get used to making some choices and decisions – but we will make them less vulnerable if we teach them they should be listened to and have their views taken seriously.

We explain how the law – the Mental Capacity Act 2005, the Equality Act 2010, Human Rights Act 1998 and the United Nations Convention on the Rights of Persons with Disabilities 2008 – offer some protection for their rights on pages 38 to 40.

Helping your child choose

As children and young people grow up, one of the most important things we can give them is the belief that they and their views matter. They'll be asked to make decisions about what they want to do and the sort of help they need as they move into adulthood. That doesn't mean we can't support them, but we do need to help them become familiar with making choices. Some of us have also found we have had to make sure that their views count when communicating with others.

'The consultant spoke to me, not my carer, and I told him the problems I had with the medication, and together we sorted it out.' (Sue 18)

Of course, not all young people can make their own decisions. Some understand things better than others. And some decisions have such far reaching consequences it's unreasonable to expect young people to make them alone.

Getting outside help

Many young people choose to share serious decisions with their parents or other close adults. But sometimes they may prefer to talk with someone in addition to, or instead of, their parent.

Brighton and Hove's Youth Advocacy Project can help disabled children and young people be heard. Advocates can go to meetings with a young person, help them to make a complaint or get legal advice. For young people with mental health challenges, Speak Your Mind has an advocacy worker who can provide support to young people aged 11 to 19 and make sure the young person's views are heard at meetings or reviews. Young people over the age of 18 with learning disabilities may be able to get help from Speak Out or Interact's advocacy services (see back for contact details).

'There were lots of things I didn't like, and I kept getting into trouble. Mum kept telling them but nothing changed. Sometimes I shouted at mum.... "you didn't tell them!" Then she said "well, you tell them yourself." A lady came and helped me think how to say what was going on and she came with me in case I got stuck. Then everyone listened. At the end of the meeting [my teacher] said she would tell the other teachers to read my plan and do it and I said I would sit away from the noisy boys. My mum said I did a good job.' (Ben 16)

Building decision making skills

Lots of young people are used to others making all their decisions for them and haven't had much practice at making

choices. Others do things out of habit, perhaps because they don't know what else is on offer, or they want to please someone, or it feels too risky to try anything new.

It's hard for young people to make big decisions if they haven't had plenty of practice making smaller ones. Making everyday decisions can help a young person become more confident at making bigger decisions later on. As a parent, you can create opportunities for your child to practise 'having a say'.

'It's hard to make choices if you don't understand what you are being asked about, if things happen without warning, and if people ignore you and don't even try to find out what you want. They talk about you as if you aren't there.' (Andrea 17)

Learning about choice

To be able to make a choice, a young person needs to know what they like. But it can be hard to express a preference about things you haven't tried - chicken tikka, for example, or a work placement at a nursery. Sometimes the best way is just to give it a go. Equally, having too much choice can feel overwhelming. Creating a balance between taking risks and making situations manageable is tricky.

If you want to help your child with making decisions, it can be useful to break things down into smaller steps. For instance: the first step towards deciding which further education course to choose could be: 'which are the full-time courses?'; choosing from a long menu at a café might be more manageable if certain items are ruled out - 'you usually don't like sandwiches or pasta'; choices about clothes to buy or what to wear can be reduced if you give extra information - 'laces are tricky' or 'it will rain later'. If the choices are still confusing, you can limit the options further.

'Dan couldn't decide which DVD to rent so I said "would it help if I gave you three to choose from?"'

Limiting options can help your child, but be careful not to reduce choices for convenience, or present them so the young person chooses the option that's going to please you or others, rather than themselves. Remember, it's not just what you say, but how you say it and what your body language suggests.

'Alice picks up on the intonation of my voice and even the order I present choices in. A lot of her speech is echolalic so I don't offer what I think will be her preferred choice last. It's about sounding interested without cueing her decision.'

We have found that talking through with our children the practical things they need - like someone to keep an eye on them, or a wheat free diet because of their allergies - can be a helpful way to practise the decision making process because it demonstrates the reasoning behind decisions. And it's a useful skill to learn for negotiating in more formal review meetings. We've also found that even when we explain something to our child, we don't always check that they have really understood, so it helps to find ways to do this.

'I say "can you tell me what you think is going to happen?" or "could you tell dad what we talked about?" That way Michael has the job of explaining it to someone else.'

PARENT TIPS

- ☺ Present a choice in small, manageable steps
- ☺ Check the choice has been understood
- ☺ Group different options together by an important common factor. So, for example, if you're planning a day

out, you might group several food options together or group together options for getting there

☺ Remember to congratulate the young person on successful decision making. Saying 'that's a good choice' conveys your pride in their ability to choose, as well as confirming that a choice has been made

Putting young people in the picture

It can be hard for young people to imagine what it might be like to do something they haven't tried before. Pictures and photographs can help them. For instance, looking through magazines could help them decide what haircut might suit them or what colour scheme for their room they'd prefer. But it can be best to experience the real thing.

'Jack wanted to paint his room red. I asked "what sort of red?" and he said "like Christmas". I took him to a friend's house because her sitting room is red. He said "It's very hot and busy, I want a quiet room" so we looked at the charts again and abandoned red!'

It's important to avoid giving young people the illusion of choice when there isn't one. This parent was prepared to go along with her son's decision to paint his room red. Be prepared to accept that they may not make the choice you hoped.

Dealing with anxieties

It can be impossible to anticipate all the things we thought the young person might be anxious about, particularly when approaching new things.

'I thought we'd talked about everything but still David refused to stay for the sleep over. I asked what else there was to worry about and he asked how he would know it was his turn in the bathroom. It just hadn't

occurred to me. Once I knew, I could help him sort it out, but it was ages before he told me.'

Sometimes our own worries are communicated to the young person without us realising. For example, our fears about their safety may contribute to a child's anxieties about new situations. And saying 'no' too often may mean they choose not to tell us what they're really doing – so we become the last to know and miss the chance to agree some ground rules.

'Chloe's friends all hang about at Churchill Square on Saturdays and of course Alice wants to go. I was really worried about what would happen if she got separated from the crowd. Could I trust her sister to look out for her? I kept saying what if this...what if that...in the end I realised the arguments were making us both miserable and she said I was treating her like a baby. We got her a mobile and put in our home number. She promised to ring me if she got lost and we've practised who it's safe to ask for help. I have to start trusting her because she starts college next year. Of course I still worry but I try not to let it show.'

PARENT TIPS

- ☺ Unpicking worries can take time, especially if it's something that doesn't make much sense to us. It's important to take all worries seriously; they arouse strong feelings and can get in the way of trying new things or making choices
- ☺ Consider the potential risks and build in safeguards. In this way the young person can take another step towards independence

A right time and place

Young people rarely make decisions they're happy with if they feel rushed or can't give their whole attention. Sometimes they're too interested in the TV, bored, tired, or feeling unwell.

Some places aren't good either; perhaps the shop's too crowded, the sales staff too persistent or the music too loud. If it's hard to hear yourself think, a young person may choose anything just to avoid the pressure.

'Tom came back with a CD he didn't want. The shop didn't have more until Tuesday but the man said "this one is just as good". Of course it wasn't, it didn't have the right tracks and Tom was very cross. He seems very able, but we hadn't appreciated that he hadn't learned to say "no thank you, I only want to buy...." After that we did some role play and practised being assertive. I remember we had a lot of fun taking turns doing the hard sell and standing firm.'

Choices as a family

Many of us find making decisions as a family has helped the young person learn about fairness, changing your mind, and living with 'majority decisions'. Finding out that it's fair for everyone to have a chance to say what they think, that it's okay to have different ideas and to change your mind as a result of hearing the views of others, is useful learning. It's also helpful to discover that sometimes you don't get your choice and have to compromise. These realities can be hard to accept, but it makes more sense to young people if pros and cons are discussed openly.

'Mealtimes, around the table with everyone, that's when we talk about big things like holidays. My priority is not too hot, Sam always wants a sandy beach and Jane wants her own tent this year. I needed to know that if she was to have a tent, she could take responsibility for her own space. We agreed that if she kept her room tidy from now on, she would have a tent of her own. Later we sat down and thought about keeping her room tidy, dirty washing, hoovering and finding a home for all the cuddlies.'

PARENT TIPS

- ☺ Negotiate a good time and place to think about important things
- ☺ Remember, choosing to take more time to make up your mind is a decision as well
- ☺ Think out loud sometimes, as this can help young people understand how to go about problem solving
- ☺ Remember, the consequences of a choice can be better understood by talking them through carefully. Having the right to choose also comes with responsibilities

INVOLVING YOUNG PEOPLE IN TRANSITION PLANNING

Although we may attend formal meetings, some decisions affecting the lives of our child and ourselves can seem to be taken without our input. To try and avoid this happening, it can really pay to take time to prepare for review meetings.

Young people are best able to contribute when they are given sufficient time to consider their wishes and feelings. It's unlikely to work if a young person is invited to attend their review meeting without preparing them.

In our experience, some professionals can struggle with empowering young people to make decisions on their own and also with taking into account their parents' views. And sometimes they don't attempt to find out what young people who have got complex communication needs might be thinking.

Young people may be the star of the show at a person centred transition review, but if they have a more traditional review, they may not be invited to all of it. Even if they won't be there though, you can still find out their views and put across how

they feel at the meeting. We assume below that they will be present – but you'll find many of the points are still relevant if they're not there for the whole meeting and you're expressing their views for them.

Helping young people plan for a meeting doesn't have to happen formally. Sometimes it's more productive to do five or 10 minutes thinking a day, over several weeks, rather than attempting longer sessions. And it's always more manageable to ask one question at a time.

'Oliver's really good at the whole education side of things, because he likes learning so he's interested in talking about what he wants to do next, what he'd like to try.'

If it's possible, ask open and not closed questions. 'Do you like that?' for example is a closed question because it invites only a 'yes' or 'no' answer. 'What do you like about that?' is an open question that invites a much fuller response.

Repeat back what you think the young person is telling you, to check you've understood them. Avoid assuming what's important to them. If it's not easy to be sure what they mean, acknowledge you've got lost and start again rather than trying to keep going when you've lost the thread.

Be patient. Resist the urge to fill silences or finish sentences. Let your child know there are no right or wrong answers and you won't be cross with whatever they want to say.

'Sometimes I'm not sure what Alice means, so I say "did you mean this, or that or something else" and I sign the choices. She uses the sign for 'different' for something else.'

Of course talking and writing are not the only means of communication. We can't assume because a young person can't speak, they don't have views and preferences. Encourage your child to choose how they want to record their views. Think about using photographs, drawings, audio or DVDs as well as observation to 'catch and record' their wishes and feelings. Simple questions in word, sign, symbol or pictures can help many young people make sense of things and order their contribution. The Foundation for People with Learning Disabilities have some helpful booklets that you can download free from their website at www.learningdisabilities.org.uk, 'Prepared for the Future?' is for parents and 'My Kind of a Future' is specially aimed at young people.

PARENT TIPS

- ☺ Check your child knows what the meeting is about, who will be there and what sort of things they may say. If you aren't sure yourself, you'll need to find out
- ☺ Make time to talk with your child about any changes in their circumstances, their needs and your needs. Take a fresh look at their Transition Plan, Care Plan or Individual Education Plan (IEP)
- ☺ It is easy to unwittingly build value judgements into questions by asking your child 'why?' Try instead to say things like 'tell me more about that', ask more open questions and repeat their answer to check you've understood.
- ☺ As the meeting gets closer, make sure copies of the young person's views - whatever the format - are circulated to everyone attending the meeting, along with your advice and those of others. Find out if your child wants to attend part or all of the meeting, or if they would like another person to present their views, and who they'd want that to be. Would they like to invite a friend or an advocate?

Setting ground rules for the meeting

Our experience is that meetings are more successful when there are clear arrangements in place that take account of a young person's particular needs. Check with the school what the ground rules are and be prepared to make your own suggestions and ask for changes if you think certain things won't work.

Ground rules before the meeting could include:

- A meeting place that's accessible and familiar
- A meeting time when the young person's best able to contribute
- Clarity over whether your child will be there for some or all of the meeting and, if they're only there for a part of it, which part it is
- The opportunity for the young person to choose where they sit
- If your child usually needs someone to interpret for them, clarify with them and the school who that will be before the meeting. It's confusing if everyone tries to help
- Agreeing what will happen if the young person wants to leave the meeting or take a break
- Getting the meeting recorded or someone nominated to take notes on your child's behalf if that's what they want
- Checking if there's anyone the young person wants to be present for only part of the meeting

Ground rules at the meeting could include:

- A reminder that it's the young person's meeting and what needs to be discussed should be central to their future
- Introducing the young person to anyone they don't know at the meeting and explaining why they're there
- Agreeing not to challenge what a young person says, interrupt them, or finish their sentences

'One of the support staff said "Chris, how can you say that?", and he just clammed up and didn't say any more.'

- Checking the young person feels their question has been answered and, if not, giving them the opportunity to ask again
- Recapping what each person has agreed to do after the meeting
- Checking the young person has understood what has been agreed will happen next

'The Casework Officer said "I'm here to write down what everyone thinks should happen next.'"

After the meeting

- Check out how you're both feeling. Maybe your child would like to go over what happened. Perhaps there is something they would like done differently next time
- Make sure your child gets a copy of what was agreed in an accessible format
- Suggest your child keeps their notes, along with the minutes and recommendations, somewhere safe, in case they want to look at them again
- If your child has clear views about important matters, make sure they're reflected in amendments to their Statement, Care Plan, Individual Education Plan (IEP), Transition Plan (TP) or EHCP.
- If it hasn't been possible to act on the young person's wishes, check who'll explain the reasons for the decision
- Encourage the young person to be involved in putting recommendations into practice

What if things go wrong?

However much groundwork you have both done, however well-reasoned the young person's arguments, and however well

supported your child has been, it's possible your child might not get what they want.

However, decisions with long term implications can and will be reviewed, and many decisions can be challenged. If you're unhappy with the decisions that have been made, this might be the time to get some professional advice. See page 22 for how Amaze can help.

WHAT THE LAW SAYS ABOUT DECISION MAKING

The Mental Capacity Act 2005

We have responsibility as a parent to decide things for our children, but once they reach 16 the law says they have the right to make decisions for themselves whenever possible. The Mental Capacity Act 2005 (MCA) is a piece of law that gives a definition of 'mental capacity' (in other words, the ability to make decisions for themselves). It aims to protect and empower people who may not be able to make their own decisions and to help parents or carers understand how and when they can act on behalf of someone who may not be able to make decisions for themselves. It covers how to decide if someone has capacity to make a decision; if they don't, how decisions should be made for them and who should be involved in this.

If people have 'mental capacity', they've the right to make their own decisions. The MCA covers major decisions including property and financial affairs, healthcare and treatment, where a young person lives, as well as everyday decisions like personal care. Some activities or decisions need more capacity than others, but very few people are unable to make any decisions, even those with severe or profound and multiple learning disabilities and high support needs. And the MCA is clear that just because someone makes a decision that other

people might think was unwise, that doesn't automatically mean they don't have capacity.

If someone doesn't have the capacity to make a particular decision for themselves, the MCA makes it clear who can act on their behalf and how they should go about it. This is not necessarily you as their parent although the act says that parents and family should be involved. For example, you might become their appointee to look after their welfare benefits, but a healthcare professional might be the decision maker for them over a health issue.

The law also states that all possible steps must be taken to help people make decisions about their lives. It explains how capacity should be assessed to decide whether a person is able to make a particular decision at a particular time, and provides a Code of Practice for someone acting on their behalf. Decisions made for the person must be in their best interest and should place the least restriction on their basic rights and freedoms.

To find out more, ask Amaze. You can also contact the Public Guardianship Office or visit www.publicguardian.gov.uk. They produce free information booklets aimed at families. Home Farm Trust has produced a good guide for carers. You can download it from www.hft.org.uk or call 0117 906 17000 to ask how to get a copy. Mencap have a guide aimed at parents of young people with more severe learning disabilities. You can download it free from www.mencap.org.uk or call 0808 808 1111.

The Equality Act and Human Rights Act

The Equality Act 2010 aims to prevent discrimination on the grounds of age, disability, gender, race, religion, sexual orientation or transgender status. It replaces the Disability

Discrimination Act 1995 and covers employment, education, public and private services, transport and more.

The Human Rights Act 1998 brought the European Convention on Human rights into UK law. Its key principles include the right to liberty, a family life and freedom of expression.

These two acts support our children's rights to respect, choice and independence in their adult lives.

The Equality and Human Rights Commission (EHRC) website (www.equalityhumanrights.com) is a good place to start if you want to find out more. The Equality Advisory Support Service (EASS) has an advice and guidance section on their website at www.equalityadvisoryservice.com as well as a helpline number on 0800 444 205.

Influencing local decision makers

Valuing People (2001) and Valuing People Now (2009) were cross government strategies for helping children and adults with learning disabilities to live full and independent lives.

The four key principles of Valuing People are:

- **Rights** - People with learning disabilities and their families have the same rights as everyone else
- **Independent living** - All disabled people should have greater choice and control over the support they need to go about their daily lives; and greater access to housing, education, employment, leisure and transport opportunities and participation in family and community life
- **Control** - People with learning disabilities need information and support to understand different options and their implications and consequences, so they can make informed decisions about their own lives

- **Inclusion** - People with learning disabilities should be able to participate in all aspects of community life – working, learning, getting about, meeting people, being part of social networks and accessing goods and services – and to have the support to be able to do so

Although the government disbanded the national team leading the Valuing People strategy, the commitment to making positive changes continues at a local level. You can influence local decision making through the Brighton & Hove Learning Disability Partnership Board the forum that was set up to make sure the vision set out in Valuing People became a reality.

The Partnership board is made up of people with learning disabilities, parent carers, support workers and service providers. It meets four times a year and links with other city planning groups to make sure issues for people with a learning disability and their families are raised. There are also smaller working groups – including a Transition Forum - that report back to the board. The Transition Forum is made up of a parent representative, an Amaze worker and a group of professionals who work to improve transition planning for young people and their families in the city. For more information contact Amaze.

Young people with learning disabilities over the age of 18 can get involved in the partnership board's work through Speak Out's Advocacy Project. Parents can influence the board's work by joining the Parent Carers' Council (PaCC). Contact Amaze to find out more..