

CHAPTER 9

Looking ahead



*It's difficult at this stage to tell what she's going to be like at 19.
Perhaps I just blot it out...*

As we said at the start of this handbook, we can't hope to include in these pages everything you need to know about having a child with additional needs, not least all the changes that might occur once your child starts to become an adult. However, Amaze and a group of parents and young disabled people have written a companion handbook called 'Through the Next Maze' which covers the transition years from 14 to early adulthood. If your child has a Statement of SEN or an EHCP in Brighton and Hove, you will be sent a copy of a mini version of 'Through the Next Maze' when they reach Year 9, to get you

started, and a copy of the full book at the start of Year 11. Otherwise, you can buy a copy from us for £9.99.

In this chapter, we will give a brief outline of what happens when your child reaches 14 and has a Statement of SEN or an Education, Health and Care Plan (EHCP). Through the *Next Maze* has much more detail about the transition planning process and covers all the other things you'll want to think about when your child is growing up, including:

- Planning for your child's future
- Involving young people in planning their future
- Further and Higher education
- Social lives and relationships
- Money matters and benefits
- Social care
- Health and medical matters
- Employment and volunteering
- Finding a place to live
- Travel and getting about

Call Amaze's helpline for a copy of 'Through the Next Maze'.

Another place to look for information about services for young people with SEN and disabilities as they move towards adulthood is Brighton & Hove City Council's Local Offer. Visit www.brighton-hove.gov.uk/localoffer.

A NEW MAZE

For some of us, it was the onset of adolescence that started us thinking seriously about the future. It's a tricky time for any parent and, as always, parents of teenagers with special needs have extra complications. Issues such as further education, relationships, sexuality, leaving home and work can be sensitive

topics. It can be useful to be armed with information about what lies ahead and begin to make plans for your child's future.

As well as adolescence being a time of great change for the child, it is also a massive upheaval for parents. Suddenly, all the people that we had come to know and rely on handed us over to a new set of professionals. Once again, we found ourselves in yet another maze, bewildered by the kinds of help available and worried that our children might not get the same level of support.

I think we're being realistic. I mean, some of us know our children are never going to be able to live independently...By the time she's grown up she'll have all these self-care skills, which she needs, but she's never going to be able to talk, so she does need to live in a very safe environment really.

All teenagers are vulnerable to outside pressures, and sometimes our teenagers with extra needs can be even more so. The natural instinct for many parents is to continue to care for and protect their children from the outside world. Of course, some of our children will continue to need a high level of adult help and support but others, like all rebellious offspring, won't let us get away with it!

And we do need to think about offering our children opportunities to take risks and to feel confident about making their own decisions. It's time to call on all sources of support and advice.

SUPPORT AND INFORMATION

Some of us lost touch with our local support group over the years. We joined when our children were first diagnosed, made friends and contacts, found our way through the system, and

gradually needed less specific support along the way. If you can meet parents who've already survived their children's teenage years, they can be a great source of strength. Those emotional and physical changes can affect children with certain disabilities in very different ways and other parents may be able to tell you what pitfalls to avoid.

This may be a good time to think about people who care about your child and who your child has a good relationship with. You could invite them to be part of a 'Circle of Support' for your son or daughter. This 'Circle of Support' could help to take some of the responsibility for helping to plan for your child's future. Person centred planning can be a good way to try and make sure your child has the sort of future that they and you want.

The other place we found useful information was through national organisations related to our children's conditions. Many of them are starting to look in-depth at adolescence and young adulthood, which has perhaps been neglected before. Some of them have useful books or publications for teenagers to read, and deal very frankly and unsentimentally with all those questions they're burning to ask, but perhaps can't ask us, their parents.

It can sometimes be helpful to us and our children if they can find good sources of support themselves, as they need and want to take more responsibility for managing their own lives. The council's Youth Advocacy project provides advocacy for children and young people, including those with special educational needs or disabilities. The Young People's Centre has an information and counselling service for all young people from 13 to 25 and it also has drop-in sessions. The YMCA's Youth Advice Centre also offers a counselling service to young people.

A good website to help young people and their parents begin to think about the future is the national Transition Information Network (www.transitioninforonetwork.org.uk).

Some children will want to distance themselves as much as they can from their differences during adolescence and teenage years, and want to be like their non-disabled peers. For others, their disabilities are a fact of their lives and will continue to be so.

As parents and carers we can do our children a great service by finding ways of enabling them, and us, to celebrate difference and diversity. Sometimes it helps young people to have contact with other, perhaps slightly older, disabled people. Positive role models, maybe people with disabilities or special needs like their own, can do a lot to show what they can achieve and what may be possible in their own lives.

We've found that schools, both mainstream and special schools, are now tackling issues raised in young adulthood in more depth. Some schools run self-awareness programmes, which cover topics like keeping safe and relationships. Many of them work hard to prepare children for the transition to adult life, and all the changes it will bring. Your child's teacher should be able to tell you what is being covered. After all, even children with severe or complex difficulties need to be prepared and have the right to be involved in decisions that will affect them.

EDUCATION AND TRANSITION PLANNING

What happens after school? It's a big worry. Christina's very happy at the moment, and I'm pleased with the school she goes to. There's no way she would be happy living at home.

All children have a right to full-time education up to the age of 19, and many children with special educational needs benefit

enormously from these last few years, whether they stay on at school or move on to a college of further education. The changes to the SEN and disability (SEND) system that became law from September 2014 give stronger recognition to this and the role of education in preparing young people for adulthood. The SEND Code of Practice 2014 gives clearer guidance to FE colleges about supporting young people with SEND. Perhaps the most important change is that Education, Health and Care Plans (EHCPs) that replace Statements of SEN continue into further education rather than stopping when your child leaves school.

Youth Employability Service Learning Difficulties and Disabilities advisers, also known as LDD advisers, should be involved with planning your child's future education and their transition through school, from Year 9 onwards. They can advise both parents and young people with SEND, whether at mainstream or special school, or at an agency placement.

Many of you will have heard about Raising the Participation Age (RPA). It was brought in by the last government (in the Education & Skills Act 2008) and has increased the minimum age at which young people can leave learning. This does not mean that the school leaving age has gone up, but since 2013 young people are expected to continue in education i.e. at a school or college or training provider or in a job with training to the age of 17. In 2015, this goes up to 18. Part-time study alongside a job, self-employment or whilst volunteering will also count.

As they get older your son or daughter should be increasingly involved in decision making about their future. From 16, the right to make decisions about education issues switches to them, although of course they will continue to rely on you to support them or act on their behalf. This also depends on whether they have the mental capacity to make those decisions - ask Amaze if you want to know more about this. But the key

point for parents is that we need to have been preparing them for this over the years by encouraging them to start to form their own views and practise making choices.

If your child has a Statement or an EHCP

If your child currently has a Statement they will need to transfer to an EHCP and there is a rolling programme to do this between September 2014 and 2018. Their Statement remains in force until this happens. Like a Statement, an EHCP is a legally binding document but it is broader; it includes more about their health and care needs. It should focus on outcomes that you and your child want them to achieve from their education including things that prepare them for life as an adult.

If your child remains in education their EHCP will cover them up until they are 19, and possibly to 25 years old, and the local authority will remain responsible for making sure they get the support set out in their EHCP. We explain more about this in the chapter about 'Education'. If your son or daughter is already at college with a Moving On Plan (also known as a Learning Difficulty Assessment or LDA) they can also change to an EHCP. Ask Amaze for advice if this applies to you.

One of the principles of EHCPs is that they should always look ahead to future outcomes for the child. From the Year 9 annual review onwards there must be an even more explicit focus on preparing for adulthood. This is often called transition planning and must look at what the young person needs to prepare them for further and higher education, employment, independent living, being a healthy adult and participating in society. This transition planning must be built into their revised EHCP. Every annual review from then on should build on this further. So the Year 10 review will include a closer look at options for post-16 education, as well as checking that the planned

outcomes in the EHCP still reflect the young person's aspirations for adult life.

Most colleges offer a range of courses suitable for some young people with special educational needs. Some of the courses are aimed at encouraging independence and social skills, some are vocational, and some can lead to a formal qualification. Parts of some courses are integrated into the mainstream work of the college so that your child can study alongside non-disabled students.

If you find that the local schools and colleges really cannot meet your child's needs, there are some residential colleges of further education, although these are limited. These are often run by independent voluntary organisations. If you want to explore the idea of a specialist residential college, your LDD Adviser can help you think about this. It will be important to get up to date information and advice about this option.

Further Education tips

Do your own research: Although you will discuss options at annual reviews if your son or daughter has a Statement or an EHCP, it's certainly worth you also doing some research yourself too. For example, you may want to contact City College to find out what courses might be suitable. They have open evenings that you and your child could attend to get a feel for the place. Disability Rights UK publish some extremely useful free information sheets about education, employment, training and other issues concerning young people with disabilities or learning disabilities.

Know what's out there and what it costs: Some of these courses will be for young people at the age of 16, while others will take students at the 'normal' school leaving age of 19 or later. Some

of the courses for over 19 year-olds may charge and you need to check if there are any costs with the college.

Think about their college-free days too: The Further and Higher Education Act requires colleges to provide courses for people with learning difficulties but these courses may not take place every day. Many colleges only offer courses for two or three days a week. The guidance for colleges in the SEND Code of Practice says young people should have a package of activities five days a week but this may not all be time in college doing traditional learning, in which case you'll need to think about what your teenager does on non-college days.

Don't forget transport: the local authority may cover the costs of travelling to and from school or college although it is not automatic, so make sure you ask about transport arrangements.

MONEY MATTERS

Most of us get extra money to help meet some of the additional costs of caring for our disabled children. Many of us get used to having this money around: it becomes part of the family budget. Often it pays everyday household bills, especially in families where parents can't work or work part time. So it's not surprising that many of us worry about benefit changes as our children grow up and the impact these changes might have on the household.

When a young person reaches 16, they have the right to manage their own money or ask someone else to do this for them. At 16 they can claim benefits for themselves. Claiming benefits in their own right has spin offs and can be the key to getting other sorts of help – but this may not be the best financial arrangement for your family.

Benefits are complicated and we go into a lot more detail about them in our Through the *Next* Maze handbook. Topics covered include:

- Changes to benefits once your child reaches 16 including DLA, Personal Independence Payment (PIP), Child Benefit, Child Tax Credit
- Advice on when your child should claim benefits as an adult
- Employment and Support Allowance
- Carer's Allowance
- Universal Credits
- Other sources of financial help
- Further help with disability benefits

Call our helpline for a copy of 'Through the *Next* Maze' or download specific chapters from our website. Alternatively, there's a large area on the website called 'Becoming an adult' which covers all the same topics. Visit www.amazebrighton.org.uk and read at your leisure.

SOCIAL CARE

As part of the education annual review when your child is 14, the transition plan for your child may also include an assessment by a social worker, particularly where he or she has complex needs. Young people with more severe learning disabilities may get support from the Social Care Transition Team.

Once children with additional needs reach 18, their support becomes the responsibility of the 'adult' social care team if they meet the eligibility criteria. A year before your child leaves school, he or she should have a social care assessment of needs. Your child's school should contact social care to let them know your child is coming up to school leaving age, and a worker

should make contact. The social care assessment of needs will involve you, your child, their teachers, any medical professionals with whom you may have contact and other professionals you may think appropriate. A complete picture of your child should be drawn up, including his or her medical, educational and social circumstances, any particular difficulties he or she has with daily living, and the family's needs for short breaks or respite. Both your own wishes and your child's hopes for the future should be taken into consideration.

In 'Through the *Next Maze*' we go into more detail about social care. Topics covered include:

- Moving from children's to adult's social care support
- Who pays for adult social care
- Social care assessments of needs
- What support is available to over 18s
- Your needs as a carer
- Young carers
- Individual/Personal Budgets and Direct Payments
- Making complaints about adult social care

Call our helpline for a copy or download the 'Social Care' chapter from our website.

It's a lovely combination now, because he lives in a group home. He hasn't got us saying 'Don't do this, don't do that'. They do their own thing. Sometimes they don't do so well, but they've got the experience of doing it, and he comes home when he wants.

HEALTH

Generally speaking, once children reach 19, they will use adult health services. In practice, some young people may already have been seen at other hospitals or community clinics from the age of 16. However, for others the transition from the Royal

Alex and the Seaside View Child Development Centre to general outpatient clinics and adult specialists may be confusing. As with other services, parents and health professionals can do a lot to pave the way and prepare the child for the change. If your child has ongoing health care needs, these should be discussed at their EHCP review meetings from Year 9 onwards.

The 'Through the *Next Maze*' handbook covers information about local adult health services including:

- Understanding the NHS
- Your child's GP
- The transition to adult health services
- Encouraging independence
- Managing medical appointments
- Learning disability and health services
- Sexual health services
- Mental health services

WHERE TO GO FROM HERE

If you have not already received a copy of 'Through the *Next Maze*', our handbook for parents of teenagers and young people, call the helpline and we'll send you one. You can get it for free if your child has a statement of SEN or an EHC Plan. Alternatively, visit our website and read through the 'Becoming an adult' section in Advice for parents - it contains most of the information from 'Through the *Next Maze*'. You can also download individual chapters there or in the Resources section under Publications/Handbooks. If you find that you still need more information and support with planning for your child's future, call our helpline.

Apart from 'Through the *Next Maze*', Amaze runs regular Parents with Teens get togethers where you can meet informally

to discuss the issues that matter to you, and courses for parents with teenagers too. See our website events listing for details of upcoming courses or groups for parents of teenagers. The Youth Employability Service and the Fed Centre for Independent Living can also offer information, advice and support. Nationally, the Transition Information Network has a website with information for both parents and young people at www.transitioninforonetwork.org.uk or ring them on 020 7843 6006 and ask for a copy of their magazine 'My Future Choices'.