Planning for adulthood and transition

As your son or daughter enters their teenage years, you will want to start planning with them for adult life. This certainly isn't a one off event – you will need to revisit your plans as the young person gets older and circumstances change.

As well as informal planning and preparing for adulthood, there are also certain points when you will need to engage in a more formal planning process.

Age 13/14: Year 9 review

The annual review meeting at school when your son or daughter is in year 9 is the formal start to the 'transition' process to adult life.

For young people who still have statements of SEN, the review will result in a separate transition plan.

For young people with Education Health and Care Plans from Sept 2014, all reviews from year 9 will have a focus on preparing for adulthood. Transition planning must be built into the revised EHCP (no separate transition plan). The year 9 review will be one of the key trigger points for moving young people from statements to EHCPs. See our Education Rights factsheets for more information.

The year 9 review will look ahead to education after age 16. For more information about some of the possible options, have a look at our page on Further education. There should however be a wider focus on preparing for adult life including:

- employment and training
- independent living and making choices
- participation in society
- support for health needs

Representatives from health and social care must be invited to the review. They may not attend unless they have had previous involvement with the young person. It is a good idea to ensure that your son or daughter is known to the local children's social care services, even if you don't need support at the moment.

Age 16: Leaving school

From 2015 all young people must stay in education or training until their 18th birthday. Many young people with Down's syndrome will attend schools which only go up to year 11 (age 16). Some people also choose to move school or go to college at this age.

It is important to start looking at colleges or other options from year 10. There is more information in our factsheet on Further Education.

Age 16: Making decisions

Many parents will already have involved their children in making choices and decisions from an early age. This can start very simply and more complex choices introduced in line with the child's age and ability.

From age 16 there is a presumption in law that people can make their own decisions unless it is proved otherwise. This comes under the provisions of the Mental Capacity Act 2005. It's important to be aware of this and to know both how to support young people to make decisions and also how decisions should be made if a young person lacks capacity. You can find more information and a factsheet on the Mental Capacity Act on the Making choices page.

Age 16-18: Health and social care

The move between child and adult health services is likely to be a phased transition between ages 16 and 18. Different services may have different age limits. During this time your son or daughter will move from the care of a paediatrician to oversight by their GP.

All adult with learning disabilities have a right to an annual health check from their GP and in April 2014 this was extended to young people age 14-17. The annual health check could be a useful way of the GP getting to know a young person with Down's syndrome better before the formal move to adult health services. You'll find more information on our Health and well-being section.

When your son or daughter is 16, you should also be thinking about making contact with adult social care. It may help if the young person is already known to children's services. Legally young people move to adult services at age 18, but recent legislation does provide for an overlap to prevent a gap in support at this point. If the young person has an Education Health and Care Plan, you should ensure that social care support is written into this. For more information on adult social care, see our page on Housing and support.

Age 19: Leaving school

Some young people with Down's syndrome may have stayed in school until age 19; others may have already been in college. In either case age 19 is likely to be a major transition point.

Under the new SEN system, young adults have increased rights in education up until age 25 and an Education, Health and Care Plan can remain in place until that age. However there is not an absolute right to continue in education. It is important to think about whether the young person wants or needs to remain in education and what a particular course might lead on to.

Look at colleges and other options at least a year before the young person leaves school. Our factsheet on Further education has information on some of the options. Be aware that funding can be difficult to obtain, particularly for residential courses and you may need to involve social care as well.

If your son or daughter currently has a statement in school, a 'transfer review' to an Education, Health and Care Plan will take place before they leave school and go to college or other training.

You should also make sure that adult social care support is in place. See the previous section.

Leaving college

It is important to plan at least a year ahead for your son or daughter leaving college. Be aware that many local authorities may only be funding courses on an annual basis, so a two or three year course may not be guaranteed.

Some young adults may be thinking about moving into paid work or volunteering once they have left college. See our page on employment for more information.

At this stage you should also ask for a review of your son's or daughter's care plan, as leaving college will be a major change of circumstances. Parents' circumstances may also have changed; you may also want to ask for a new carer's assessment. See our page on Housing and Support for Adults.

This is also a good time for parents and young people to think about increasing independence from the family and the possibility of moving out of the family home.

According to the Mental Capacity Act (2005), anyone over 16 must be presumed able to make decisions for themselves, with support if needed, unless it can be shown otherwise. Mental capacity is not a 'blanket decision' – it is situation and time specific. This includes decisions about managing money and bank accounts.

Further information

Preparing for Adulthood has lots of downloadable resources for parents and young people.

Transition Information Network aims to improve the experience of disabled young people's transition to adulthood.

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