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spina bifida
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Transition

A Guide for Parents of Teenagers with
Spina Bifida or Hydrocephalus



This guide looks at the transition process, which starts in year 9 of your child's education.

Parenting a teenager can often prove challenging, but there can also be particular difficulties if you are a parent of a child with additional needs.

Up to now, you have probably been used to being in control, making decisions, speaking to professionals, accessing additional funding and resources, on a regular basis, for your children, with little or no input from them.

The move from junior to senior school often unleashes children into a more independent environment and schools actively encourage children to be independent. Teachers no longer come to them to teach, children now have to orientate themselves around school to find the teacher. They have to organise their own timetables, ensure their homework is in on time and generally keep up with their peers. Children also become aware of how they compare to others and are keen to compete on not only an intellectual level, but a social level too.

It was acceptable to have a parent or carer coming in and out of primary school to ask for help on a pupil's behalf, but at

senior school, it is perceived to be 'un-cool'. Transition is an ideal time to take a fresh look at your child's changing needs as they enter into adulthood, to take stock of what they want, their feelings, and to try to guide and support as opposed to making decisions for them.

Transition meetings are not just about education, they can be an ideal place for planning a young person's move towards thoughts of independent living and the financial implications involved. There may be some areas that your son or daughter may feel uncomfortable discussing in front of a panel of 'strangers'. This could be about their personal care, friends or lack of friends and social life and, as much as parents often like to avoid the subject, sexual relationships.

As parents, we all strive to contribute to our children's unique development. Giving them the opportunity to take responsibility for their own actions and decisions is the biggest contribution we can make.



One of a series of booklets on transition to adulthood and employment for those with spina bifida or hydrocephalus, funded by The City Bridge Trust



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Preparing for the transition process with your son or daughter

Prepare for the transition process well in advance, encourage your son or daughter to keep a written account of thoughts, feelings and questions they may like to discuss at the transition review.

Compile a list of names and contacts of people that may have been involved in your child's formative years. These could be family friends, teachers or professionals, such as GPs, occupational therapists, speech and language therapists etc.

Children often find it difficult to recall names, but given a list of options, you will be able to signpost them in the right direction and with careful steering, invite a panel of people who will represent and provide a true picture of your child's needs. For example, your son/daughter may suggest his/her speech and language therapist. Encourage the young person, with positive points such as "that's a good idea, remember how much she said your speech had improved over the past year". Always begin with the positive but do remind them of any constructive advice the person had - such as "and remember she said you must keep practicing with the letter 'r'", etc.

It is helpful to include a written account of your son's or daughter's personal achievements - academic and sporting/ social. Encourage them to keep a record of their own achievements, to include clubs, hobbies, awards etc. We often forget the smaller achievements and a booklet is a good way to reflect on 'how far you have all come' on those negative days.

Think about how information is delivered to your son or daughter when talking about these ideas. Are they better with visual or auditory memory? Adapt to their needs. So many young people have computers today, so make a simple visual and tailor-made list of all the things we have spoken about. Try laminating the print-offs and encourage your son or daughter to make any alterations or thoughts directly on the sheet, using a dry-wipe pen. Take this into the Transition Review and again encourage them to refer to this for further discussion.

Once your son/daughter has established their own aims and thoughts with regard to what THEY would like to cover at transition meetings, it is a good time to raise some more sensitive issues. Hopefully their self-esteem and confidence has been raised sufficiently to tackle these areas.

As a parent you know your son/daughter's needs inside out and gentle coaxing will encourage them to be honest about themselves and their future needs.

A tick list of people whom you may want to include in the Transition Review:

- Teachers
- Speech and Language Therapist
- Occupational Therapist
- Educational Psychologist
- Paediatrician
- Family friends
- GP
- Social Workers
- Physiotherapist



Personal Care

A very tricky subject when you are trying to be 'one of the crowd'. You need to check that the facilities available for personal care are acceptable during the rest of their time at school and at any college they may be considering.

A young person may be reluctant to admit that they have needs for their personal care and certainly will not be happy discussing them in the Transition Review. It would be a good idea to ensure that the panel receives a copy of your questions and concerns before the review. This way, answers can be to hand at the review and avoid any un-necessary confrontation and discussion.

Developing Interests and Hobbies

After-school clubs and hobbies are an ideal way of integrating people and developing social skills through mutual interests.

You may find that your son or daughter has an interest or hobby that is not entirely age-appropriate, but that they still wish to pursue this area. Again a letter beforehand, asking about the possibility of starting a new after-school club, or additional input from a teacher may help with answers for your son/daughter at the review meeting.

Assisting academic learning

Do not be afraid to ask about alternative formats that may assist your son or daughter with their learning through

their teenage years. There are so many formats available today, Braille, British Sign Language, picture forms and even interpreters. If you feel they will benefit with the use of additional or differentiated forms of learning, put your ideas forward.

You have probably made decisions quite happily about many of these matters in the past, but now is the time for inclusion in a different way, inclusion of your son's or daughter's hopes and aspirations. It is time to re-address your child as a young person, look closely at their changing needs as they begin their transition into adulthood.

It is always difficult to let go of our children and particularly difficult when a young person with spina bifida and/or hydrocephalus embarks on the transition period and ultimately the beginning of an independent life.

For years you have no doubt attended every medical appointment, agreed and supported independent education plans within school and taken the decision that 'parents know best', in the BEST interest of your child!!

Transfer from primary school to senior school appeared to run smoothly. You implemented your parental skills and ideals, yet suddenly, Year 9 approaches and the views of 'your child' must be included in the transition plan.

Sharing information

The sharing of information is an important tool for your son or daughter to learn and take into adulthood. Life is about sharing information, asking questions, discussion, compromising and keeping us 'in the picture'.

What is the Transition Plan?

Think of it as an 'action plan' - a way forward to assess the needs and support required through education in the teenage years and into adulthood. By law, this plan should be drawn up when a student reaches National Curriculum Year 9.

Information is collated by a series of professional bodies that have been involved in your son's or daughter's life and will include parents and, of course, the young person themselves.

The first transition plan is usually discussed at the annual statement review in Year 9 and should be updated every year until the young person leaves school. However, if your son/daughter continues through to further education, this support can be continued.

The Code of Practice states that following the first Transition Planning Meeting, subsequent annual review meetings should continue to plan services and provisions required post 16.

Who will attend the Transition Planning Meeting?

Anyone involved with the young person.

If they are attending school, the headteacher or SENCO (Special Education Needs Co-ordinator) will write to everyone involved. This will include the parents too and will be a way of collating information and a history of your son's or daughter's needs and, of course, highlighting their

strengths too. Social workers and health professionals will also be contacted.

Please do not think of this as an intrusion, all this information is to enhance your child's transition to adulthood.

The Special Educational Needs Code of Practice says that the headteacher must invite the following people to the review:

- The parents or guardian
- School staff who know the student
- Connexions personal adviser, who must attend the Year 9 review
- A representative from the LEA
- A representative from the social services department

You may also wish to invite additional people, a friend or mentor who may be able to support you or your son/daughter throughout the meeting. Do not forget to invite any professional person who may have been involved with your child, e.g. speech and language therapist, psychologist etc., and ensure you have notified the headteacher of your request.

The most important person in this review is of course 'the young person'. They may wish to attend the meeting about their future and there is no reason why they too, should not submit their own views and thoughts about future education. Encourage the young person to write down their feelings

and thoughts independently, this is the time to put forward any anxieties and worries, (some of which you may not even be aware of!).

Remember, some of the people attending the review may not know your son or daughter very well. It is therefore important to build 'a picture' of their strengths as well as weaknesses to ensure appropriate support is understood. We are often so keen to tell everyone how well our children are doing that access to educational and financial entitlements are often overlooked.

Connexions

Connexions is a service for young people aged 13 to 19, and some people can receive support up until they are 25.

The Connexions Service has a key role in the development and delivery of the Transition Plan. The young person should have their own Connexions personal adviser who will help them talk about and explore their own options for further education, training and work. The adviser will ask questions to help find out how they can help and is there to assist in making choices. You will probably meet the Connexions personal adviser for the first time at the Year 9 review - another good reason for encouraging your son or daughter to attend the meeting.

Key to successful transition – and all free!

Transition requires a variety of ingredients to succeed and mistakes will be made along the way. But as with making a successful cake, ensure the basic ingredients are always included and these can be added free, by supportive parents and carers.

Security – this can go a long way towards encouraging young people to feel safe in their surroundings

Opportunity – every opportunity and experience encourages confidence and although success is important, it is also OK to fail

Praise – young people still need praise and encouragement to give them the motivation to try

Communication – include verbal interaction with family conversations and non-verbal such as body language and facial expressions.

What do you need to think about?

A Ask

I Investigate

M Motivate

S Succeed

Ask as many questions as you feel necessary, through family, friends and professionals.

Investigate areas of education and career planning, through the Internet, local businesses and the library.

Motivate the young person by setting ‘tasks’ to encourage their independence, confidence and self esteem.

Succeed by setting achievable goals and learn to negotiate and compromise about realistic requests.

Questions and issues to consider

- Make a list of questions which you may wish to ask
- Remember this is not what YOU want, include the young person at all times, encouraging decisions and interaction
- Take along any relevant information from school e.g. record of achievements, this will help qualify the young person’s strengths
- Use medical documentation/ reports from GPs, speech and language therapists etc. these will help support any areas of additional needs
- If your son or daughter might be reluctant to speak, perhaps ensure they have pre-written their thoughts and ideas about continuing their education or possible careers
- Are they thinking about residential colleges, if so, what about transport, living arrangements
- Will they require specialist equipment, who will provide and maintain it
- Are they receiving all the benefits, will they be affected by college or part-time work (Education Maintenance Allowance www.ema.dfes.gov.uk), a very useful website to look at)
- School – additional academic support, applying for additional time or alternative requirements e.g. scribe required for exams

One parent's personal experience of the transition process

- Position of seating in classroom, noise, lighting, visual prompts
- Disability Rights Commission – covering examinations and assessments
- Work experience – enquiries and preparation in advance with regard to access and accessibility, especially toilet facilities and lunch/canteen facilities
- Further Education – types of courses, part/full-time – consider individual health and stamina needs
- EGAS (Education Grant Advisory Service) offering guidance and funding for those studying in post 16 education
- Transport – are colleges easily accessible, possible residential colleges
- Consider the use of Higher Rate Mobility DLA for car
- Interview, CV writing and associated techniques
- Direct Payments – over the age of 16

As a parent to a child with special needs your apprenticeship in advocating on their behalf starts the moment you get told 'there's a problem'. By the time they get to their teenage years you are well versed in this skill and your experience of having a child at school is something you share with others. However, as other parents are readying themselves for 'empty nest syndrome', parents of young people with special needs are having to step up their fight to ensure that their particular nest is not seen as the safety net into which the failure of local services fall.

A lot is written about transition and so I assumed that post transition review there would be regular information, monitoring and planning but this was not the case. I got good advice from my child's school, and from the Connexions agent but that was pretty much it. A transition plan was mentioned but this wasn't done till my child was 16 and a half. It dealt very much with personal details and history up to then but not much about my child's personal aspirations or those of the family. The best advice and support I got was from other parents who had gone through the same process a year or so before me and were willing to share what they had learned.

The transfer from paediatric to adult medical services was well handled with each department telling me where and to whom her case was being transferred.

This was quite emotional as many of them we had seen regularly through good and bad times and had taken a personal interest in our lives.

One of the most frustrating things about looking at FE colleges is securing funding. We are currently visiting various colleges, getting to meet new people, discussing what a great opportunity it will be with my daughter thus raising her and our own expectations but knowing the decision about the funding will probably be made by people who don't know her and this is hard.

My advice to any parents would be:

- 1 Central to the whole process is your son/daughter. Involve them as much as they are able. You are teaching them to take control of their lives.
- 2 Start making enquiries early. Many colleges have waiting lists or different timetables for admission so start early not to be caught out.
- 3 Get advice from support groups or organisations that deal specifically with these issues.
- 4 Speak to other parents who have been through it. Their knowledge is invaluable.
- 5 Listen to experts, they may have the answer to your questions but never doubt your own expertise which you have acquired along the way.

Further information

Other leaflets in this series are:

- *Transition - A Guide for Young People with Spina Bifida or Hydrocephalus*

- *Getting a Job*

- *A Guide for Employers.*

It is suggested that parents and their son or daughter refer to both the guide for parents and the guide for young people. All the leaflets are available to download from ASBAH's website at www.asbah.org or as printed copies – available from ASBAH's helpline, telephone 0845 450 7755

You might also like to read ASBAH's information sheets:

What is Spina Bifida?

What is Hydrocephalus?

Going to College with Spina Bifida or Hydrocephalus.

Other useful resources and sources of support

Connexions

Website: www.connexions-direct.com

This is a government funded organization that gives career advice for students with disabilities up to the age of 25. Each Connexions service has access to a specialist adviser who supports young people with disabilities.

Education Maintenance Allowance

www.ema.dfes.gov.uk

After 16 – What's Next?

A guide for young people, parents and carers - www.after16.org.uk

Joseph Rowntree Foundation

www.jrf.org.uk

Transition Pathways

www.transitionpathway.co.uk

Hurtling into a void: Transition to adulthood for young people with complex health and support needs. (1999) Jenny Morris.
www.pavpub.com

Transition Guide – The Council for Disabled Children
www.ncb.org.uk/cdc

Skill, National Bureau for Students with Disabilities

Head Office
Chapter House
18-20 Crucifix Lane
London SE1 3JW
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Skill is a national charity which promotes training and employment opportunities for disabled students and adults.

Mencap Education and Employment Service

6, Nightingale Court
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Telephone: 01709 830 956
E-mail: eebu@mencap.org.uk
Website: www.mencap.org.uk

Mencap education and employment service consists of four different services. They range from residential courses to enable students to lead a more independent life, day activities and voluntary work opportunities, to providing work trails, preparing students for the world of work and helping people find employment.

Modern Apprenticeships

Website: www.apprenticeships.org.uk

Modern apprenticeships offer people over the age of 16 the chance of paid employment linked with the opportunity to train for jobs, usually in the areas of craft or technician, eg electrician, carpenter, plumber etc.

Volunteering

Website: www.volunteering.org.uk

Volunteering opportunities not only enhance your working and life skills, they can often lead to other employment opportunities.