Many pupils with Arthrogryposis (AMC) have a STATEMENT OF SPECIAL EDUCATIONAL NEEDS and will thus have gone through a detailed multi-professional examination to find out exactly what their special educational needs are. It includes educational, medical and psychological advice and advice from social services and from other agencies. Parents are also asked to give a report.

The final statement is split into 6 parts:

Part 1 Introduction gives your child’s details
Part 2 Special Educational Needs outlines any areas of difficulty your child experiences
Part 3 Special Educational Provision should give details of all provision to be made directly relating to all needs listed above and arrangements for monitoring progress
Part 4 Placement School, or other provision, the child will attend, to be left blank in proposed Statement
Part 5 Non-educational Needs those agreed by social services, health or other agencies and the LEA
Part 6 Non-educational Provision gives details of non-educational provision, e.g. by health, social services or other agencies, and how it will be met

Annual Review
All statements (other than those for children under 2) must be reviewed at least annually. The annual review is to discuss both the progress the pupil has made and whether any changes need to be made to the statement. Parents’ and pupils’ views are an important part of the review. When a child is moving on to secondary school parents’ must know by 15th February of the year of transfer which school their child will attend.

Pupil’s Views
The United Nations Convention on the Rights of the Child says that children who are capable of forming views have a right to receive information, to give an opinion and to have that opinion taken into account in any matters affecting them. The Code of Practice (2001) supports this and says that children should, where possible take part in all the decision-making processes that take place in education. This includes: setting learning targets, choosing a school, contributing to the assessment of their needs, the annual review and transition processes.

Moving to Secondary School
Moving to Secondary school can be daunting in many ways, and common issues amongst pupils with Arthrogryposis are:
• Carrying heavy bags and needing to move around a much bigger area – this may impact on energy levels
• Wanting learning supporters to stand back as much as possible so that peer friendships are not affected
• Having many more teachers, learning supporters and other members of staff who need to be made aware of any education or care needs

**Mobility Solutions**

If a pupil has mobility problems it may be worth considering a powered chair, which will enable them to:

• conserve their energy for study and friendships
• keep up with their peers
• be more independent of their learning supporters

Other pupils may need to rely on their manual chairs more than when at primary school.

**Pupil’s Information Booklets**

It is essential that a pupil’s views are taken into account when preparing for the move to Secondary school; meanwhile it can be difficult to make those views known to so many people!

One way around this is to produce a ‘booklet’ that can be passed to the new school before joining.

This would be useful to all members of staff but especially the SENCO and learning supporters. It can also take some of the pressure off the pupil who, whilst wanting things to be done a certain way, may find it both tiring and difficult to have to repeatedly make their wishes known.

Working on such a booklet gives the pupil and their parents an opportunity to focus on how they would like the new school to support them. They might want to involve staff from the current school too. It is an opportunity to express specific wishes on personal care, to impress upon the school that when assistance is not needed helpers should stand back, and even to clarify any preferences where language is concerned e.g. ‘assisting’ rather than ‘looking after’; ‘accompanying’ rather than ‘taking’; ‘having AMC’ rather than ‘suffering from’!

Possible headings and topics might be:

• About me, my hobbies and likes and dislikes
• About my disability and how it affects my school day
• Information about being a wheelchair user at school
• About my privacy – information for personal care assistants (i.e. confidential!)
• General Information on AMC for Schools*
• Specific information on AMC*
• Growing up with a physical disability – what it’s like*

*The last three documents are available from TAG.
Useful Organisations

**Contact a Family**
Information and support to the parents of all disabled children.
Tel: 0808 808 3555
www.cafamily.org.uk

**ACE (Advisory Centre for Education)**
Free guidance and advice on all aspects of state education.
Tel: 0808 800 5793
www.ace-ed.org.uk

**CSIE (Centre for Studies on Inclusive Education)**
Information and advice on educating children with special educational needs within ordinary schools.
Tel: 0117 328 4007
www.csie.org.uk

**DfES (Department for Education and Skills)**
Publishes statutory guidance on education and provides a range of useful information.
Tel: 0845 60 222 60
www.dfespublications.gov.uk

**Education Otherwise**
Support and information for families whose children are being educated outside school.
Tel: 0870 730 0074
www.education-otherwise.org

**IPSEA (Independent Panel for Special Education Advice)**
Has independent experts who give advice to parents and carers who are uncertain about, or disagree with, the LEA’s views of their child’s special educational needs. They offer a free representation service.
Tel: 0800 018 4016
www.ipsea.org.uk

**Network 81**
Information, guidance, help and advice on the Education Act and special educational provision.
Tel: 0870 770 3306
www.network81.org

**Parents for Inclusion**
Promotes the rights of disabled children to attend local mainstream schools.
Tel: 0800 652 3145
www.parentsforinclusion.org