Education in Noonan Syndrome

BACKGROUND
Much of this information is by courtesy of Sheila Laverick. Sheila is a parent of a Noonan Syndrome son and is also a Special Needs teacher. In 2002 Sheila analysed a survey which was sent to parents by BDF Newlife regarding their experiences with Noonan Syndrome and education. Therefore this fact sheet is split into 3 sections.

SECTION 1
The following information is an extract from an article by Sheila Laverick published in SNIP (Special Needs Information Press) Newsletter issued May 2003.

WAYS FORWARD IN THE EARLY YEARS SETTING
Specific attention is likely to be required to enhance abilities in motor development. Problems may be experienced in achieving toileting skills, dressing and undressing and using implements such as pencils, felt pens, paint brushes, scissors etc. Manipulative play, such as threading beads, construction and moulding, will need to be supported in order to reduce frustration, with attention paid to levels of difficulty to ensure success. Imaginative play may also be restricted, but could be encouraged with such devices as the use of peer and adult modelling, role play and puppets. Plans need to be developed that identify the small steps needed to gradually achieve competence. Liaison with home regarding reducing threats to success by the revision of clothes and shoes that do not have button and laces can be helpful. Occupational Therapists (OT) can be useful in identifying/providing suitable motor programmes and resources to help support developing skills.

KEY STAGE 1 AND 2
Poor sitting posture and difficulties in balancing may present difficulties, so attention to provision of appropriate seating and positioning needs to be paid. Again, observation and advice from the OT or Physiotherapist would be useful here. Pencil and implement skills will remain weak, so any activity that requires good hand-eye control such as writing, drawing and painting may present difficulties. Provision of appropriate resources such as thicker pencils, grips and a sloping surface may help pupils to achieve success. Consider physical education (PE) - this needs to focus upon identifying and achieving gross and fine motor skills through the gaining and recognition of individual competencies. Classroom issues such as supporting the ability to be responsible for organising self, by ensuring that storage is at an appropriate height, need to be considered. Regarding learning competencies - individual strengths and weaknesses need to be identified in order to encourage success. Particular attention needs to be paid to ways of supporting the recording of work - copying from the board, for example, is likely to present significant challenges and devices such as providing word frames would be useful. Improving literacy and numeracy abilities should take into account, learning style and utilise many of the strategies suggested for those who indicate dyslexia, e.g. over-teaching, the continued use of concrete apparatus, multi-sensory programmes and the identification of software resources to provide high levels of rehearsal.
KEY STAGE 3 AND 4

Consider whole school issues after discussion with all involved. These may include paying attention to the provision of appropriately sized furniture, such as ground-level lockers, and reducing the amount of books that have to be physically transported around. Timetables may need to be colour coded and home liaison arrangements regarding homework timetable and other issues relating to parental and pupil concern, need identifying and instigating. Curriculum considerations increasing the awareness of Noonan Syndrome and the pupil's specific profile to all staff. This may mean organising additional training and the publication of fact sheets to support the effective inclusion of the pupil that identify suggested areas of difficulty, e.g. specific language deficits, poor motor control and difficulty in co-ordination.

For all pupils with NS, teasing regarding physical appearance can be very distressing. Increasing pupil awareness of the unacceptability of this behaviour by reference to the anti-bullying policy needs and its rigorous implementation must be undertaken. Locating buddies to support pupils, establishing a safe haven and working with the pupil to pro-actively reduce the areas where problems may occur are also useful strategies.

Finally, pupils with NS may need time away from school to attend medical appointments, to recover from illness and for hospital visits. This can be problematic because it reduces and disrupts both social contact and school work. Clear arrangements need to be agreed and recorded regarding completion of work and maintenance of contact with peers.

WHAT IMPLICATIONS ARE THERE FOR SCHOOLS?

Pupils with NS indicate a range of physical and cognitive impairment that need appropriate action to be decided and implemented. This will require consultation and liaison with parents, the child, the external experts involved such as speech and occupational therapist, plus LEA support services. Identification of needs and action necessary is likely to require the drawing up of a Health Plan, particularly if medication has to be taken.

Those with NS may display many characteristics of developmental disorders such as dyspraxia, dyslexia, attention deficit hyperactivity disorder and autistic spectrum disorders. These include:

- Concentration, attention and impulsivity difficulties
- Short term memory problems
- Receptive language difficulties
- Repetitive behaviours and dislike of change
- Visual/spatial difficulties
- Social immaturity
- Attention needing
- High levels of fatigue
SECTION 2

THE RESULTS OF THE SURVEY

In analyzing the results of the survey which were sent to parents in 2002 the highlights of the survey are as follows:

1. Age of diagnosis
   The survey data showed that in the post 16 years age group the average age of diagnosis was age 5-11 and there are some noted cases of diagnosis much later in life. However, in the pre-school and younger children groups diagnosis ranges from anywhere from birth and 6 months. This indicates that diagnosis has over the years been earlier.

2. Which School
   For the children in the survey, this showed that 68% of the children were in mainstream schools. 20% attended a special school, 7% attended a specialist resources unit (probably for a specific disability) and 5% were in other forms of education.

STATEMENTING

Of the replies we received 45% of the children had or have educational statements.

THERAPY

The biggest area reported for therapy interventions is speech therapy at 40%. 62% also reported that they have or have had physio or occupational therapy. With 22% being occupational therapy and 24% being physio. This means that 46% of children have had or are having some form of additional therapy. 14% reported that their children had received therapy through Portage. It is interesting to note that the Portage programme seems to be on the increase. The survey of the children in the early years shows that about half of the pre-schoolers are following or have recently followed a Portage programme to develop their basic skills.

EDUCATION ASSESSMENTS

Over 55% of children have seen an educational psychologist, 12% had been assessed for hearing difficulties, while 5% had been assessed for visual impairments affecting their education. In respect of the educational psychologists in just looking at the primary school years the survey shows that in fact over 70% of those children in key stage 1 and 2 had seen an educational psychologist. This indicates that most Noonan children are now referred to an educational psychologist for an assessment before or during the primary school years.

SPECIFIC LEARNING DIFFICULTIES

Most parents reported that they thought the biggest problem was with handwriting and expressing themselves on paper (recording). Over 60% of parents recorded this. 58% of parents reported problems with tension difficulties. Around 57% reported problems with reading difficulties. In respect of maths, spelling, multiplication tables 50% reported difficulties with these. Art and PE were also reported by parents as being problematic with just under 50% showing this.

Language remained reported as a major problem with receptive and expressive language difficulties being reported by 45-47% respectively. Handwriting was a specific problem that was reported by parents at primary school, this would seem to...
SOCIAL, EMOTIONAL AND BEHAVIOURAL DIFFICULTIES

Parents reported that they believed the biggest difficulty was with poor self-esteem. This perhaps had an impact on the reported difficulties in children making and keeping friends; over a third of the children experienced problems with these particular friendship issues. However, a quarter of the parents reported their children had what they would describe as behavioural difficulties. The survey interestingly showed that parents believed that difficult behaviour was more of a problem during the primary school years than the secondary school years.

FATIGUE

Nearly 50% of all of the parents who responded in the survey, reported that their children suffered fatigue relevant to the long school day. We have no data to show whether those parents reporting this had specific problems with cardiac involvement, which may impact on this fatigue. Therefore the results may be skewed by this lack of data.

HEIGHT

Nearly 30% of the parents responding felt their children's short stature was a problem at school.

BULLYING

The results of this section of the survey must be treated with great caution. People's perception of the word bullying varies greatly and parents were reported a variety of situations, some serious, some very minor which have all been tagged with the overall term bullying. The survey showed that 30% of the children had some form of physical based bullying. However, we do not know the level, degree or true incidence of this situation. We also do not know how this compares to national statistics.

SECTION 3

OVERALL POINTS

The physical effects of having Noonan's Syndrome in respect of skills such as spatial skills, co-ordination skills, problems with speech, sequencing etc may have a greater and wider effect of the child's education experience than would normally be expected. This is perhaps due to the complexity and overlap of many of the symptoms of Noonan's Syndrome. Adjustments to the height of tables and chairs may be advantageous in some school settings. However, many children move from classroom to classroom according to subject and it is not always practical to achieve this. Some parents have outright reported that special chairs and tables designed to do this actually act to highlight the child's short stature to the other children more so than is beneficial in the overall. OT assessment for writing implements etc can be very beneficial. Careful assessment by key experienced staff should be made with Noonan's Syndrome taking into account their muscle tone, any hyper extension or mobility of joints and fatigue levels. Accounts should also be taken of poor spatial skills, so that work can be done on this in a more private setting so that the children are not outwardly vilified for being very poor with these skills. In the early years problems with buttons, clasps and laces etc, should be addressed by parents so that these difficulties do not cause problems at school. It is reported that children with Noonan Syndrome often appear to understand words and structures, but invariably
when tested there comprehension level is less than was thought. This sometimes gives problems in gaining co-operation with children. Many children will have multiple hospital visits to be co-ordinated. School first aiders should be aware of the risks of heavy bleeding and heart associated anomalies.

Further information on any of these aspects can be gained by contacting the Noonan Syndrome Association on 0800 083 2972.