

## NOONAN FACT FILE

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## USEFUL INFORMATION FOR PARENTS- CONTINUITY OF ASSOCIATED CARE AND SUPPORT FOR THE CHILD WITH NS

Children with Noonan syndrome can have a vast amount of medical and developmental difficulties to deal with, ranging from mobility, sight and hearing problems, to specific learning difficulties, short stature and severe heart problems, to mention a few.

Many of these children make frequent clinic visits and may have to stay in hospital on occasion. These frequent unavoidable absences from school can cause disruption to the child both emotionally and educationally. It may become apparent that the child is in need of extra assistance within nursery or school.

Gaining the initial support that many of these children require to enable them to maintain an adequate degree of performance stability within a classroom situation is often a long drawn out procedure fraught with confusion on both sides as to the best way of meeting the individual child's specific needs - no two children with Noonan syndrome would have the same degree of difficulty within a given area.

Once the support is established the importance of continuity for child and support worker should not be underestimated.

We are aware that many children with Noonan syndrome have difficulty with:

- communication skills
- spatial skills
- sequencing events
- co-ordination
- concentration
- obsessive and repetitive behaviour
- short term memory
- immature behaviour
- handwriting
- reading
- poor muscle tone

basic comprehension, i.e. relating a command or ruling to themselves, or understanding a set of instructions.

Continuity of support is essential if the child is to have the best possible chances of achieving his/her potential.

As Noonan syndrome is such a complex condition with a wide variety of behaviour patterns, the ongoing support and established rapport of someone who has worked with the child for a number of months and even more so, years, has to be vital to that child's well-being. The knowledge and trust built up between the support worker and the child is so important a bond that it should, wherever possible, be allowed to continue for as long as viably possible. This especially important in the case of pre-school and primary school children who do not readily take to changes in the daily pattern of things. They tend to show repetitive behaviour and do not adapt well to a change of routine, with the stubbornness feature of the condition coming to the fore, often with confrontational results.

Bringing in a new support worker, particularly after a long period in the care of another, can, in many cases, be detrimental to the child. Initially from the obvious aspect of a 'getting to know you' or 'assessment' period that sets the child's progress back quite considerably, and, also from an emotional point of view, the child has to 'educate' a stranger who may take several weeks or months to understand the specific behaviour and learning difficulties of the child. This situation may build up a frustration in the child who possibly cannot communicate their needs or thoughts easily and may

result in a falling behind and a lowering of self esteem, not to mention the distress they feel from losing their 'friend - who understands... what, why and where'.

All of this can cause an immense upheaval in the life of a child who becomes unhappy and their whole character and behaviour may be affected. They may wonder why they have to have a new support worker, wrongly imagining that they are to blame for that person going away.

Any major change in the continuity of support given can have far reaching long term effects and should be discussed fully with the parents, the child and, ideally, the support worker involved. It is not an issue that can be entered into lightly.