

### Noonan Syndrome

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Noonan syndrome is thought to occur in as many as between one in every 1000. The syndrome, a genetic disorder, has a number of features which vary in individuals. Both sexes can be affected. The syndrome was first reported in 1963 by Dr Jacqueline Noonan with a close association of a specific heart defect, short stature and unusual facial appearance.

#### **Effects on Developmental Areas**

##### **Social and Emotional Development**

- May have slow social development due to increased hospitalisation for heart defect diagnosed at birth
- May have poor social skills due to delayed language development and acceptance by peers because of unusual facial features
- May show characteristics of stubbornness and irritability
- May lack self-esteem
- May prefer to socialise with children younger than their age

##### **Language and Communication Development**

- May have language difficulties of speech articulations and language delay
- May not readily *understand* or *use* appropriate forms of communication including verbal language, body language, facial expression, tone of voice and gestures
- May have limited or no speech and/or lack typical communicative gesture

##### **Physical**

- May have congenital heart defects such as pulmonary stenosis, atrial septal defect or Ventricular septal defect
- May be at the lower end of the of the growth range thus short in stature
- May have widely spaced eyes with drooping eyelids which may affect vision
- May have a short neck and loose folds of skin in the nape of the neck
- May have low set ears and distinctive lobes which are bent forward
- May have a flattened bridge on the nose
- May have poor muscle tone giving rise to weak sucking in the early months to clumsiness in childhood
- May have undescended testes in boys
- May have a squint and myopia
- May have hearing loss

### Cognitive

- May have learning difficulties
- May not stay long at activities due to low concentration span
- May have delays in skills of concentration, memory and ability to generalise
- May have difficulty understanding concepts of turn taking, sharing, how to enter into play situations

### Noonan Syndrome Inclusion Strategies

Each child diagnosed with Noonan Syndrome will be different and individual. It is important to gain information from the parents as to what characteristics of Noonan Syndrome their child displays. It is important to work closely with the parents as well as any additional support specialists e.g. therapists who may be involved with the child. It is also important to gain an understanding from the parent as to what is the most important aspect of their child attending your service. What is it that parents hope to gain from using your service? The following inclusion strategies are just some examples which may be applied to support the inclusion process. This list is only the start and it is dependant on a variety of factors such as environment, length of time child is in care, child's interest, likes, dislikes and skills already achieved. The strategies are divided into developmental areas however some strategies overlap and assist in a variety of developmental areas.

### Social and Emotional Development

- Use strategies to assist children separating from parent e.g. set a routine in saying goodbye, finding a book to read.
- Value and acknowledge child's efforts.
- Let other children know what child is doing to reinforce the concept of him being part of the group. Do this with all children e.g. "Look Jack is doing a puzzle as well".

### Physical Development

- Keep things in the same place to assist child to be able to move from one place to another. If you change the environment walk and talk this through with the child.
- Plan physical activities for times when child is most energetic.
- Provide simple obstacle courses that the child is capable of completing to experience success.
- Provide finger plays to encourage the use of both hands in a controlled manner as well as developing fine motor skills.
- Plan for fine motor developmental tasks with adaptive equipment such as a non slip mat under the drawing paper, thick crayons, and thick handled paint brushes that are easy to grasp.

### Language and Communication Development

- Encourage children to talk about what they are doing by asking several times throughout the day. Also, ask children to tell you what you or others are doing.
- Provide positive reinforcement during play times and encourage dramatic play.
- Provide clear directions and break into manageable steps in sequence.
- Use picture or object system for organising the daily events and encourage children to sequence - establish a comfortable routine.
- Utilise the use of large clear pictures to reinforce what you are saying.
- Para-phrase back what the child has said.
- Clarify types of communication methods the child may use e.g. Makaton.
- Label areas in the room with words and pictures.
- Use sequencing cards to support children's learning of how to predict what comes next and associate events.
- Provide puppets/pictures as an extra prop when using finger plays and songs.
- Reduce the amount of instructions in one statement to allow time for the child to gain an understanding of what is been said e.g. "Hold the puppet up high" rather than "hold the puppet up high and wave it around so that all the children can see it." Once child understands to "hold the puppet up high" you can then add "Good, now all the children can see it".
- Ascertain from parents words that are familiar with the child e.g. family words that represent aspects of child life and use these in your program.

### Cognitive

- Avoid generalisation.
- Use concrete representation to enhance concept development.
- Focus and reinforce relevant information, aspects, attributes and characteristics.
- Allow the child time to complete tasks and practice skills at own pace.
- Acknowledge level of achievement e.g. "you have placed that piece in the puzzle, well done" rather than just "Good boy".

#### Reference

**"Noonans Syndrome"** Birth Defects Foundation UK

Gilbert P (1996) ***The A-Z Reference book of Syndromes and Inherited disorders*** Thornes

Deiner, P.L. (1993) ***Resources for Teaching Children with Diverse Abilities - Birth through Eight.*** Harcourt Brace:

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