

Turner Syndrome

Turner Syndrome is a genetic disorder that affects females. It is caused by a missing or abnormal X chromosome. This results in short stature and infertility. Other symptoms can include congenital heart defects, spatial awareness issues, hearing or eyesight problems, slower sexual development and puffiness of the hands and feet. Intellectual ability is usually not affected. The severity of this condition can vary widely depending on the abnormality of the chromosome. Due to these variations, the condition may be diagnosed at different life stages from before birth right through to adulthood.

With appropriate treatment and support however, it is possible to lead a normal and healthy life with this condition.

Developmental Areas

Children may display some of the following characteristics

Social and Emotional Development

- May have low or limited understanding of social interaction with peers
- May have difficulty in making friends due to physical appearance and language delays
- Social development can also be delayed due to health issues resulting in the child being absent from educational settings
- Child may have limited peer initiated social experiences

Physical Development

- May be short in stature making activities difficult
- May have visual impairment
- May have hearing impairment
- May have gross and fine motor difficulties such as catching and throwing balls
- May have unusual weight gain through hypothyroidism
- May have bouts of feet and hand swelling due to faulty lymphatic drainage

Language and Communication Development

- May have frequent bouts of Otitis media (inflammation of the middle ear) thus affecting hearing and communication
- Speech may slow with a hoarse voice
- May have difficulty with conversation

Cognitive Development

- May have had limited concrete experience with the environment
- May have learning disabilities particularly in the cognitive understanding of word comprehension and mathematical concepts

Health and Safety Issues

- Be aware of health implications that may affect participation in aspects of the program
- Short stature can be increased with medication however may present educational problems particularly physical education
- Otitis Media should be adequately monitored and treated
- May be under medication for the hypothyroidism
- Weight gain can also be an issue
- May suffer from coarctation (narrowing) of the aorta

Turner syndrome Inclusion Strategies

Each child diagnosed with Turner syndrome will be different and individual. It is important to gain information from the parents as to what characteristics of Turner 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? 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

- Encourage and plan for positive social experiences (small group experiences etc.).
- Allow the child ample time to complete tasks independently.
- Encourage children to ask questions and allow time for responses.
- Promote the opportunity for children to explore play materials.
- Provide musical experiences that allow for emotional expression.

Physical Development

- Provide an area with clear, uncluttered spaces.
- Be aware of the child's *medical* physical needs.
- Ensure the environment is safe and secure promoting easy access.
- Provide appropriate materials and equipment to support the child e.g. support chairs at the appropriate height and adjustable tables.
- Provide toys that are easy to grasp and manipulate including puzzles with large knobs or floor puzzles with large pieces - manipulation aids can be added for children who unable to isolate finger movements or control wrist movements.
- Provide tactile or sensory experiences that the child can cope with and present these at a level appropriate to the child's development e.g. tactile balls such as urchin or koosh balls.
- Use musical instruments to stimulate sensory development.
- Plan smaller, manageable experiences for the child that may be an activity or game divided into smaller achievable tasks.
- Be aware of the child's abilities when providing obstacle courses etc. for the whole group and provide opportunities for children to explore movement in different ways.
- Watch for signs of fatigue and avoid children becoming over tired.
- Plan quiet and busy activities indoors and outdoors to include children's varying capacities for attending to different experiences.
- **Stabilising** toys for children can enhance function. Toys can be stabilised by clamping their bases to tables, using masking tape to secure them to the surface, using a non slip mat such as Dycem or securing with suction caps or velcro.
- **Grasping aids** can be used to make objects more manageable. Velcro can be placed around the child's hand and the object to create a bond between the hand and the object. Wrap foam or tape around items to make them easier to hold.
- **Boundaries** can be created by restricting the movement of toys e.g. using a track with edges for push and pull toys etc.
- **Switches** can be adapted to battery operated toys for children who have extremely limited hand function.

Language and Communication Development

- Encourage staff and children to become familiar with and utilise the child's communication system and utilise the combination of gestures, pictures with words used.
- Provide alternative forms of communication such as picture boards and use photos of resources available in the program.
- Provide ample language activities to assist in the language development.

Cognitive Development

- Provide instructions and direction in sequence allowing child to undertake each instruction one at a time.
- Provide memory games and a small group of problem solving activities e.g. puzzles
- Provide opportunities for child to work with one other child to solve problems e.g. how can we get the sand from the bucket to the wheel barrow? Use this time to encourage math concepts.
- Use concrete activities to reinforce concepts.

Health Issues

- Coarctation of the aorta must be corrected surgically. If this occurs staff must consult with parents any implications that this may cause while the child attends the service.
- Ongoing checking for signs of delayed hearing should be noted and parents informed.
- Ensure staff are aware of what medications and medical therapy the child is undergoing.

References

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