Leber Congenital Amaurosis

Leber Congenital Amaurosis is an inherited retinal degenerative disorder that causes an infant to be born with severely impaired vision. The infant may also be born with or develop roving or jerking involuntary eye movements. Children may poke their eyes or press on them with their fists or fingers. This may lead to misshapen and thinned corneas and a sunken appearance of the eyes.

The level of vision remains stable once childhood is past. Vision may only be at the level of seeing light and dark or detecting hand motions. Diagnosis can be difficult and can be hard to distinguish what is vision and what is behaviour in an infant or child. ERG testing is important in measuring if the child can see and how much.

There is no significant treatment and the child may benefit from the use of low-vision aids.

Effects on Developmental Areas

Social and Emotional Development

- May lack a certain amount of independence
- Children who use alternative forms of communication may have been exposed to limited social interactions with peers who are not familiar with the alternative communication systems
- May lack interpersonal skills
- Need to develop socially acceptable behaviour
- Lacking in self esteem
- Inappropriate use of language
- Certain aspects of time management may be lacking
- May startle easily

Physical Development

- May experience delayed motor development due to inability to participate in experiences independently
- May have had limited experiences that promote motor development
- Some children may have delayed gross and fine motor co-ordination
- Lack certain aspects of spatial awareness
- May not demonstrate environmental awareness
- Children may not be able to move around independently
- May frequently fall over

Language and Communication Development

- Certain aspects of communication may be delayed
- Forms of communication may be different
- May hold objects close to face or bend head down close to the table surface

Cognitive Development

- Cognitive development may be delayed due to lack of concrete experiences
- Concept development may be lacking if children are unable to visualise experiences
- Child may prefer to stay at one activity centre and avoid trying new tasks
- May avoid textures of tactile activities such as finger painting, goop etc.

Leber Congenital Amaurosis

Inclusion Strategies

Each child diagnosed with **Leber Congenital Amaurosis** will be different and individual. It is important to gain information from the parents as to what characteristics of **Leber Congenital Amaurosis** 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

- Encourage peer initiated interactions by other children.
- Encourage children with visual impairment to initiate interactions in appropriate ways and explore ways that they can attract other children's attention.
- Provide positive reinforcement for children's social attempts.
- Promote independence by using strategies and resources to encourage children to complete tasks on their own - a tactile time table may enable a child to select their own activities independently and tactile footsteps or wall marking may assist children to move independently to different activity areas.
- Teach specific skills that facilitate access to the environment and develop increased independence.
- Adjust the environment to suit the child and be aware of lighting issues.
- Be aware of inappropriate mannerisms.

Physical Development

- Provide tactile stimulus on obstacle courses and other playground resources to encourage children to walk, climb, crawl, jump etc.
- Add safety mats to obstacle courses to maintain a safe environment.
- Provide materials and equipment that the child can easily manipulate.
- Adapt activities as required to include all children e.g. use a variety of paintbrushes for painting with thick handles, short handles etc.
- Provide tactile experiences where children can explore space and various forms of movement e.g. finger-painting.
- Modify equipment as required and utilise adaptive technology.

Language and Communication Development

- Become familiar with child's communication system.
- Teach and reinforce listening skills and non-verbal communication.
- Observe the child before approaching him and warn the child before touching to avoid unexpected response.
- Use a normal volume and tone with a clear voice.

Cognitive

- Provide materials in an appropriate format e.g. concrete, tactile etc.
- Teach consistent routines.
- Purposefully expose children to a range and variety of experiences with opportunities to engage all senses through interactions with the environment Education Qld (1988:17).

Reference

Umansky, W. and Hooper, S. (1998) ***Young Children with Special Needs*** Third Edition New Jersey, USA:Prentice-Hall

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

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