



ROYAL NEW ZEALAND
FOUNDATION OF
THE BLIND

TE TUĀPĀPĀ O TE HUNGA KĀPŌ O AOTEAROA

A WORLD OF THEIR OWN

**Communication tools that enable
children who are deafblind and
have CHARGE syndrome to travel
safely in their environment**

Alana Bogart



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CHARGE Syndrome

The term CHARGE describes a recognized pattern of birth defects

Coloboma

Hear

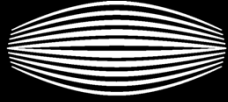
Atresia

Retardation

Genital

Ear





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A Combination of Characteristics

- Deafblindness
- Vision impairment due to colobomas
- Difficulty with communication
- Behavioural disabilities due to developmental delay
- Poor balance
- Tactile defensiveness



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Case Study One



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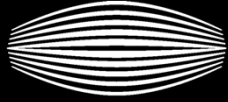


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Communication Wall



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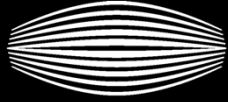


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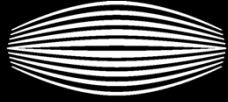
Communication Tools



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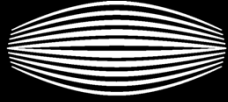


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Footpath Travel



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Case Study Two



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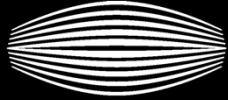
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Multi-Sensory Impaired

Children with CHARGE present:

- at different levels of cognitive ability
- at different levels of independence
- with a varying ability to interpret their surroundings



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One Size Does Not Fit All

each programme must be tailored
to the child's individual needs

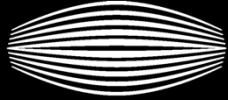


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Take A Holistic Approach

- caters to the child's current and future needs
- developed in conjunction with other professionals
- acknowledges the child's needs, goals and expectations
- acknowledges parent's, family's and support network's goals and expectations

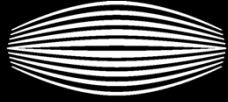


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Communication

- experience difficulties with speech
- may have/had a tracheotomy
- find it difficult to give verbal feedback

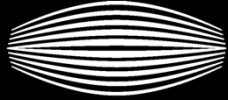


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Behavioural Disabilities Due To Developmental Delay

- high level of anxiety and inflexibility
- OCD-like and autistic-like behaviours
- misinterpret environmental information
- may over-react to external stimuli
- impacts on language acquisition



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A World Of Their Own

Any programme must be

- Flexible
- Individual
- Relevant

The programme must take into account

- the world the child inhabits
- the child's needs, goals and expectations
- the goals and expectations of their parents, their family, and of their support network



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Thank You

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Please feel free to ask any questions

Have a great day