

# LEARNING DIFFICULTIES IN CHILDREN WITH NF1



The information provided below is a summary of the presentation given by Dr Belinda Barton on 7 March 2020 at the NF Information Day in Sydney.

Dr Barton is a paediatric psychologist whose major research interest is in understanding the cognitive and psychosocial aspects of genetic and neurodevelopmental disorders. She is particularly interested in neurofibromatosis type 1 (NF1) and leads the NF1 cognitive research program and the NF1 Learning Disorders Clinic at The Children's Hospital at Westmead.



## WHAT ABOUT LEARNING DISORDERS IN CHILDREN WITH NF1?

Research shows us that 50-80% of children with NF1 will have some form of learning or behavioural challenge that impacts upon their education.

Parents need to identify the specific needs of their child. This is done from discussions with teachers and formalised assessment by specially trained psychologists.

Cognitive and behavioural difficulties in children with NF1 are variable:

- Not every child will have learning difficulties
- Not all strategies or interventions will work with every child
- The earlier learning difficulties are identified and treatment is implemented, the more likely that better outcomes will be achieved
- Up to 80% of children with NF1 demonstrate problems in at least one area of cognition, such as attention, visual perception and executive functioning. Learning difficulties are the most common complication of NF1 in childhood.
- There is a significantly higher occurrence of reading disabilities (~65%) and ADHD (30-50%) in children with NF1 when compared to the general population.



## DO CHILDREN WITH NF1 STRUGGLE WITH READING AND/OR DYSLEXIA?

Reading is a complex process and is challenging for many children with NF1. Parents often report that problems with reading, comprehension and spelling are one of their biggest concerns for the child's development.

There are three forms of Dyslexia - phonological, surface and mixed.

- **Phonological Dyslexia** is present in nearly half of all children with NF1. This is when children have difficulty in reading regular words (i.e. 'real' words that obey letter-to-letter sound rules). Examples of words include BED, TREE, LONG.
- **Surface Dyslexia** is slightly more common than phonological dyslexia in children with NF1 and encompasses difficulties in reading irregular words (i.e. 'real words that disobey letter-to-letter sound rules). Examples of words include ISLAND, COLONEL, YACHT.
- **Mixed Dyslexia** is a combination of difficulties in reading regular words and is less common in children with NF1.

The team at Westmead are studying 60 children with NF1 between the ages of 7-12, and found that 82% of these children are poor word readers and almost half have some form of dyslexia.

They have evaluated specific, computerised reading programs such as Lexia, Multilit, Reading Eggs, etc. and have found that children improved in their reading ability when using one of these programs, and maintained these results eight weeks later.



## WHAT ABOUT COGNITIVE & EMOTIONAL ABILITIES IN CHILDREN WITH NFI?

### **Executive Functions**

Executive functioning refers to the set of cognitive skills that are necessary to control behaviour. These include planning, organisation, problem solving, working memory and emotional self-regulation and awareness. Many children with NF1 have difficulty in one or more of these areas.

### **Working Memory**

Working memory continues to develop in children until early adulthood. Problems usually start becoming apparent at around 7 years of age, and are often associated with poor academic performance and attention problems.

Working memory exercises and training can increase working memory capacity. Training helps children get better at the specific tasks for which they are trained. However, it does not seem to help children perform better in other associated areas like reading or mathematics.

Children with working memory difficulties have trouble understanding large amounts of verbal information, arithmetic, carrying out tasks or instructions with multiple steps, and keeping track of what they are doing or saying.



## ARE THERE ANY STRATEGIES THAT CAN HELP IMPROVE WORKING MEMORY?

Below are some instructions that can help to improve a child's working memory:

- Simplifying and frequently repeating verbal information
- Providing visual instructions as well as verbal
- Breaking down tasks into smaller sub-routines, so children can tackle just one component at a time
- Training should target the specific tasks that are difficult for your child
- Cognitive intervention programs have proven to be helpful. For any program, see if there is the evidence showing that the program works and if it is effective in improving other skills (e.g. academic performance). Examples of proven training programs include:
  - » [Lexia](#)
  - » [Multilit](#)
  - » [Literacy Planet](#)
  - » [Reading Eggs](#)
  - » [Jolly Phonics](#)
  - » [Mathletics](#)

**If you have any questions regarding this information, our Support Team is available to help. You can reach them via phone on **(02) 9713 6111** or by email at [support@ctf.org.au](mailto:support@ctf.org.au)**

**You may also wish to contact the Learning and Cognitive Disorders Clinic on **(02) 9845 3057.****