

## Learning Problems in Neurofibromatosis-1

Scott Hunter, PhD, Jim Tonsgard, M.D.

### Why Is It Important to Evaluate Learning and School Performance in Children with NF1?

- Up to 60% of children with NF-1 have problems with some areas of learning or attention span.
- Children with NF-1 can have other problems that can affect function in school:
  - Coordination problems can make it harder for them to write or draw
  - Speech problems make it harder to understand what they say
  - Difficulty with socialization and peer relationships can affect school performance

### Watch Your Child's Development

- As your child grows, it is very important to follow his or her development carefully as well as how he or she is doing in preschool and school. Children can differ in terms of when they develop or learn to do or say different things, but it is helpful to be alert to whether your child seems to be “keeping up” with the other children of the same age or seems to be behind.
- If you have young children, you should become familiar with the developmental milestones for infants and toddlers. Studies of young children have shown that most children master a variety of tasks at specific ages. For example, most children can say 3 words other than “mama and dada” by 15 months of age. Your pediatrician or family doctor will be asking about these developmental milestones (using the Denver Developmental Screening Test) and if your child seems to “be behind” then you should ask to have your child evaluated.
  - In most states, developmental testing is done without charge by the state early intervention program.
  - After 3 y.o. children with learning problems are the responsibility of the local school

### Start Looking at Learning Early

- Early intervention programs provide therapy and do make a difference.
- Speech problems deserve early attention. Don't wait for school to work on this. Problems with speech affect how other children and adults interact with your child.
- Speech problems are sometimes due to problems with the mouth, palate, or lower brain. They should be evaluated.
- Talk to your child as much as possible. Parents who are the most verbal/talkative, have the most verbal children.
- Encourage early reading ability: recognizing letters, numbers, the sounds of different letters, even learn some words.
- If your child is in preschool or school, ask the teacher how your child is doing, is he or she learning and interacting in a way that is similar to the rest of the children, does the teacher feel your child is “behind” in some areas.
- If your child is “behind” in school, ask to have your child evaluated. This is done for free in the public schools and evaluates your child's strengths and weaknesses by a team that usually includes the teacher, the school psychologist, therapists, and social workers.

## What Symptoms Are Frequently Seen in Children With NF-1 with Learning Problems?

Certain symptoms may be helpful in alerting you to the possibility that your child may have learning problems. If you see some of these problems you should discuss them with the child's teacher or your doctor. The symptoms of learning problems in NF-1 include:

- **Short Attention Span, Trouble Concentrating, Distractible**
- **Learning difficulties**
  - Difficulty with Math
  - Difficulty with Reading/Problems Sounding out Words
  - Difficulty with understanding reading (comprehension)
- **Speech problems**
  - Speech is unclear, or words are clipped off, or very nasal sounding
- **Motor coordination difficulties**
  - Trouble with printing or writing or holding the pencil
  - Low muscle tone
- **Behavioral problems**
  - Hyperactive, restless
  - Impulsive
  - Difficulty with organization
  - Mood swings, temper tantrums, and anxiety

## Problems with Attention Span are Common in NF-1: The Attention Deficit Disorder

Approximately 40-60% of children with NF-1 have the **Attention Deficit Disorder** (with or without *hyperactivity*). This may be due to both structural and functional problems in the brain of children with NF-1 that affects the networks or "circuitry" that connects certain areas of the brain together. This can make processing information slower or less efficient. This can make it harder for children to maintain sustained attention (*vigilance*). They can also have greater distractibility so that they make errors that are due to skipping over questions (*omission*) rather than answering incorrectly. Children also have difficulty with shifting attention from one task to another quickly. As a result, problems with attention span can affect how information is taken in and then "encoded" in the brain. Attention span problems can affect reading and listening comprehension.

## Additional Features of Attention Deficit

- Children with Attention Deficit also frequently have behavioral issues such as *impulsivity, distractibility, and restlessness*.
- Children with Attention Deficit also frequently have problems in **Executive Function**. Executive Function includes flexibility, speed with which you process information, making good choices (problem solving), controlling impulsiveness, organizing tasks and information.
- Medicines can help attention deficit
- Redirection and behavioral approaches are also useful

## Learning problems in NF1

- Children with NF1 can have IQs in the normal or superior range, but generally speaking IQ scores tend to be in the normal to low normal range, often they are lower than their normal siblings.
- One-third of children with NF1 have no learning problems.
- Mental retardation and Autism are not common but occur in some patients with NF1.
- Commonly kids with NF1 have specific learning disabilities. These are specific areas of weakness that are greater than would be predicted on the basis of a patient's IQ.
- It is important to understand both the strengths and weakness in learning in order to help children learn more effectively.

## Specific Learning Disorders in NF-1

- **Language Disorder**

Children with a language disorder have difficulty expressing themselves (verbalization, elaborating or explaining ideas) and difficulty listening and understanding or remembering spoken information (auditory processing). They may have problems with attention span.

- **Reading Disorder**

Difficulty with reading is common in NF-1. It often occurs in children with Language Disorder (see above). Children may have difficulty "decoding" letters or words (dyslexia). From a practical standpoint, this means that some children with NF-1 learn to read by memorizing words (non-phonetic approach) rather than learning to sound words (phonetic approach). Besides difficulty with "decoding" words, some children with NF-1 can have difficulty understanding words or sentences (comprehension).

- **Mathematics Disorder**

Problems with Math are noted in 60% of studies looking at learning problems. Children with Mathematics Disorder often have *visuospatial* and *visuoperceptual* problems. They also frequently have problems with attention span, organization, and other executive functions (see above).

## Dyslexia and Problems with Phonetic Approach to Reading

- People with dyslexia may mix up the order of letters: "saw" may look like "was"
- Letters may appear blurred
- Sometimes the order of words in a sentence is mixed up.
- The phonetic approach to reading can work for words like "bus" where you make the sound for each letter separately "b", "u", "s", but it doesn't work for words like "phonetic" where the "ph" sounds like "f". Children with NF commonly have problems with this type of phonetic approach. A phonetic or phonemic approach is felt to be essential to successful reading, but for the NF patient, it may be more difficult and require a smaller student-teacher ratio, close monitoring, teachers trained in specific learning programs (such as the Lindamood Phoneme Sequencing Program, see below), and intensive practice with emphasis on phoneme decoding to build decoding skills and building memory of "irregular" (i.e., non-phonetic words) and intensive work on reading comprehension.

## Executive Function Problems

This involves identifying strategies to solve problems and then implementing the strategy as well as having flexibility if the problem changes and judging whether the strategy has worked. Executive function includes a number of areas or skills such as working memory, inhibition, processing efficiency and attention span and memory.

People with executive function problems require support in both school and home. Coaching by licensed clinical and school psychologists is helpful. Coaches try to help children break down tasks into manageable parts and to see how the parts can come together to form a complete task. Parents can learn to help children in a similar manner to break down tasks and then put them together. Written schedules, outlines, and task guides can also help to remind children of individual tasks. Tutors can also help by reinforcing problem solving strategies for school work as well as working on reading comprehension, written expression, and mathematic problem solving skills.

## Behavior Problems in NF-1

- Behavior Problems are common in children with NF-1, especially hyperactivity.
- Conversely, kids with NF can appear to be shy, awkward, or isolated (loners). They may appear more immature because they have problems interacting with others (social skills).
- Children with NF1 can have poor adaptive skills (leadership)
- Behavior problems in NF1 should be identified early to try to understand the cause.
- There are specific therapies that can help with behavioral and social issues.

## School Performance

- Ask the teacher frequently how your child is doing.
- If the teacher feels that your child is having problems:
  - Ask to have him or her evaluated: Individual Education Plan (IEP)
- Be aggressive or proactive regarding school. You may or may not want the school or teacher to know about NF.

## How to Request an Individual Education Plan (IEP)

- Sign a request in the principal's office and keep a copy to prove when you made the request
- The school has 60 working days to respond to your request.
- The school does have the right to refuse to do an IEP.
- The school may request to do an initial intervention to see if simple changes help learning.
- It helps if you have a teacher or therapist on your side who agrees that an IEP is needed.
- Make sure that your doctor reviews the IEP when it is completed. The quality of evaluations varies and if your school doesn't do a thorough job, you may need to get private neuropsychological testing.

### **What is Neuropsychological testing?**

- Neuropsychological testing is a group of tests that look at:
  - How your child processes information (sees, hears, and retains information)
  - How your child organizes information or facts
  - How your child decides what to do with information
  - Whether your child is impulsive or distracted.
- Neuropsychological testing also tests basic issues:
  - Reading and reading comprehension (grade level)
  - Math abilities (grade level and concepts)
  - How he or she learns new words
- Neuropsychological testing assesses your child's potential to learn, not just what he or she knows.
- Good neuropsychological testing makes recommendations on how to help learning (identifies tutors, coaches, speech therapists, people to help with social skills)

### **What Is a 504 Plan?**

- Schools are required to provide resources that are appropriate for each individual child
- Some children have difficulty learning because they have physical conditions that affect learning:
  - Asthma, arthritis, cerebral palsy, vision and hearing problems
  - The 504 Plan provides services for those kids even if they don't have cognitive problems.
- However, many schools try to avoid doing IEPs because they require a complete evaluation and therefore take time and are expensive.
- A 504 Plan does not require any evaluation or testing , it simply provides some services.
- This may be better than nothing, but it doesn't help to understand why a child may be having difficulties in school.

**See Learning Resources on the next page.**

### Resources for Learning Problems

- Learning Disability Association: [www.ldanatl.org](http://www.ldanatl.org)
- National Center for Learning Disabilities <http://www.nclld.org/>
- Children and Adults with Attention Deficit Disorder (CHADD): [www.chadd.org](http://www.chadd.org)
- Attention Deficit Association: [www.add.org](http://www.add.org)
- LD Online <http://www.ldonline.org/>
- LD Pride <http://www.ldpride.net/>
- Handwriting Without Tears <http://www.hwtears.com>
- Local NF clinics
- Pediatric neuropsychologists at major medical centers

### Programs for Learning Problems

- Commercial tutoring programs using the [Orton-Gillingham](#) approach
- [Lindamood Phoneme Sequencing Program](#) for reading, spelling, and speech, Austin, Texas: PRO-ED, Inc.
- [Phono-Grafix, Reading Reflex](#).
- [PHAST Track](#) program for severely delayed older readers
- Lumosity – Brain training exercises for any age. \$14.95 per month; \$5.99 per month if paid yearly.  
[www.lumosity.com/about](http://www.lumosity.com/about)

The most effective intervention for reading involves early identification of children “at risk” and programs which work on phonemic decoding to building decoding skills, build a working memory of irregular words (that are not phonetic), and a systematic approach to reading comprehension. Successful intervention also depends on practice, teacher training, and emotional support.