NF Tennessee's

NF1: A RESOURCE FOR TEACHERS

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Neurofibromatosis Type 1

Cause

Neurofibromatosis Type 1 (NF1) is a genetic disorder that affects approximately 1 in every 3,000 children. Neurofibromatosis is caused by genetic mutations that can be passed on to an individual by a parent or can occur spontaneously during conception. In NF1, genetic mutations occur on chromosome 17, altering a gene that typically produces a protein, neurofibromin, which normally functions to regulate cell growth. Due to these genetic mutations, neurofibromin is reduced and does not function properly, causing cells to grow abnormally. Many types of cells are affected by a deficiency of neurofibromin function, especially cells in the brain and nerves, skin, bones, and blood vessels. There is also a strong tendency for benign tumors, especially on nerves, called neurofibromas, and also of some types of cancers.

Symptoms & Medical Considerations

NF1 typically presents in early childhood, with noticeable symptoms distinguished at birth, during early childhood, or generally, before the child is 10 years old. Though 80-90% of individuals with NF1 are diagnosed by age 10, a few individuals with mild versions are diagnosed between ages 10 and 20, and only very rarely after that. *Common symptoms and medical considerations include:

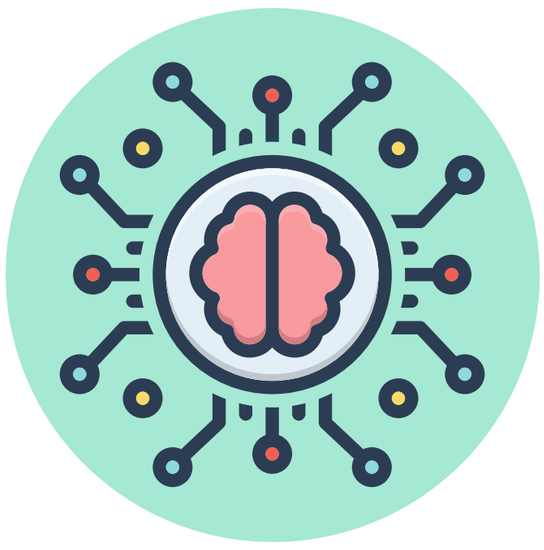
- **Café au lait spots** – Individuals diagnosed with NF1 typically will have café au lait spots which are light brown spots that lie flat on the skin.

* Individuals with NF1 will have some, but not necessarily all of the symptoms listed.

- **Armpit/groin freckling** – Children with NF1 will usually have excessive freckling, particularly around the armpit and groin regions, starting when they are between 3 and 5 years old.
- **Lisch nodules** – These are tiny bumps that are on the iris of the eye, however, they are harmless and do not negatively impact the child's vision.
- **Neurofibromas** – These are soft, small bumps that form under the skin or can grow inside of the body. Although these tumors are benign, they can cause disfigurement. They tend to appear in the early teens, and also increase during pregnancy, suggesting hormonal effects. Large soft versions called plexiform neurofibromas are more likely to enlarge with age and can produce aggressive cancers.
- **Bone deformities** – Individuals with NF1 can experience deficiencies in bone density which can lead to scoliosis.
- **Optic glioma** – An optic glioma is a tumor that forms along the optic nerve which can impact vision.
- **Shortness in height** – Children with NF1 typically have a shorter stature.
- **Larger head size** – Roughly 50% of children with NF1 will have a larger sized head from increased volume of the brain.
- **Learning difficulties** – Children with NF1 often experience difficulties with learning. Though deficits in IQ typically range from mild to nonexistent, 30-50% of children with NF1 have significant intellectual disability, with about 5% having an IQ < 70.

Learning Difficulties

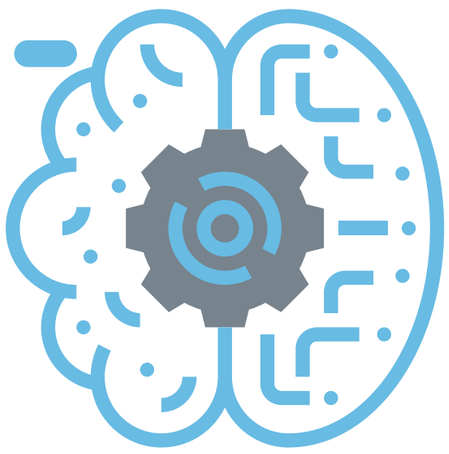
Around 50-60% of individuals with NF1 experience some form of learning difficulty. Many students with NF1 have normal levels of intelligence with specific difficulties in reading, writing, or in using numbers. This document will go over the following areas impacted by NF1 that can affect a student's learning within the classroom:



COGNITIVE

PHYSICAL

BEHAVIORAL



Executive Functioning

Executive functioning relates to our cognitive skills. These kinds of skills are used to solve problems, analyze tasks, simplify them into steps, and remember them for a later time. We utilize executive functioning skills to manage time, memorize information, comprehend what we read, and also to organize our thoughts. Individuals with NF1 often struggle with tasks requiring executive functioning skills like figuring out how much time to spend on an assignment or getting organized.

Teaching Tips & Supports

- **Visual representations & manipulatives** – You can support your students with problem solving difficulties by using visual representations or manipulatives.
- **Active verbalization** – Strategies (e.g., think aloud, self-questioning) where students verbally articulate what they do/don't understand can help them with problem solving.
- **KWC charts** – These charts are a type of graphic organizer that has students answer the following: What do I Know about the problem? What do I Want to know in order to solve the problem? What are Challenges preventing me to solve the problem? KWC charts help students think through the problem-solving process.
- **Timers** - Providing your students with timers can help support them manage their time.

Teaching Tips & Supports Continued

- **Self-management** – This intervention involves self-instruction, self-monitoring, and self-evaluation. With self-instruction, students learn to provide themselves with their own cues to carry out a task (e.g., verbalizing did-now-next procedure "I did put my backpack away, I need to take out my math assignment, I'm going to get my math assignment"). Self-monitoring involves the student identifying, monitoring, and recording whether a target behavior (e.g., remaining on task, initiating a conversation) has occurred or not. Self-evaluation relates to goal setting where a student compares their performance of the target behavior with an established goal (e.g., student evaluating if they met the goal of correctly completing 5 math equations within time period). Self-management can also include self-reinforcement where a student gives themself a reinforcer (e.g., computer time, verbal praise, break) when the goal is reached. These strategies can support task organization, time management, and problem-solving skills.
- **Task analytic instruction** – Task analyses break down complex processes/skills into discrete, manageable steps. This strategy can be used to simplify tasks in various domains (i.e., math processes, reading strategies, social skills techniques, classroom organization).

Visual Perception

Individuals with NF1 often exhibit visuo-perceptual difficulties - a characteristic feature of the diagnosis. Common domains of visual perception difficulties in children with NF1 include:

Visual-Spatial Analysis

Visual-spatial processing is the ability to determine where objects are in space as well as how far away something is in relation to another. These skills are utilized to complete tasks like reading a map or completing a math problem. To solve a math problem like "5 + 25 = 30", a child must use visual-spatial processing skills to perceive how the numbers and symbols are placed in relation to one another. Similarly in reading, these skills help students understand that "w" and "m" or "6" and "9" represent different sounds/values. For children with NF1, such skills are difficult. For example, a triangle turned at different angles is still a triangle, however a 6 flipped is 9 which has a different value. Children with NF1 struggle with understanding the difference in how the position of an object can affect its value.

Visual-Spatial Analysis

Teaching Tips & Supports

- **Simplify materials** – Reduce the amount of visual input you put on your materials (e.g., presentations, worksheets, screens) and do not add unnecessary effects that can distract your students.
- **Provide templates & use scaffolding** – For students that have trouble reading or interpreting graphs/tables, you can support them by providing templates and then scaffolding support so the student can use templates on their own.
- **Models & visual supports** – Providing models and visual supports that your student can easily access like an alphabet or number chart can help them with inverting or reversing their numbers and letters
- **Consistent visual spatial formats** – Consistently organizing how you present information can help students easily find and process it (i.e., always posting the homework assignment on one part of the board)
- **Bookmarks** – You can support students that skip lines, lose their place, omits words, or rereads lines by providing bookmarks to help with tracking.
- **Manipulatives** – You can support students that have trouble connecting math concepts by using/providing manipulatives or 3-D models to help visualize and interpret the information
- **Graph paper** – You can help your students that have trouble writing in a given area or spacing their words by providing graph paper so they can visualize each letter for each square.

Spatial Learning & Memory

Spatial learning and memory involve the processes needed to learn and store information related to location and orientation. These processes are involved in tasks like remembering where the light switch is in the bathroom or remembering how to get to school from your house.

Teaching Tips & Supports

- **Maps & observable data** – Have your student observe stable visual data throughout the school/classroom (i.e., count the number of rooms on the way to the bathroom) and create maps of the school/neighborhood noting distinguishing features (i.e., restaurants)
- **Repetition** – Repeating instructions, prompts, models, tasks, and routines can help your students remember the information more easily and process it.
- **Graphic organizers** – Provide your students with graphic organizers (i.e., story maps; KWL charts) to help them arrange information to support their understanding/ remembering of the material

Cognitive Concerns

Visual-Motor Integration

Visual-motor integration (VMI) is the ability to interpret visual information and then produce a motor action in response. In other words, VMI is the effective communication between the eyes and the rest of the body. For example, VMI is needed to correctly perceive and copy letters, numbers, or shapes onto a piece of paper.

Teaching Tips & Supports

- **Slant boards** – Providing a slant board can support students with difficulty copying through elevating the writing surface to support tracking, positioning, and grasp when writing.
- **Differentiate instruction** – Provide your student with different modes of presentation for assignments (i.e., oral reports; visual presentation; collages)
- **Handouts** – Provide handouts of notes/materials to reduce copying tasks
- **Speech-to-Text/ Audio recordings** – Allow students to use speech-to-text apps or audio recordings to support note taking and to reduce copying

Perceptual Organization

Perceptual organization involves the process of giving structure to what we experience (objects, scenes, and events) in the world. Children with NF1 may have difficulty with sequencing information in an order that makes sense, figuring out the meaning of symbols and words, organizing new information, and understanding abstract concepts.

Perceptual Organization

Teaching Tips & Supports

- **Self-questioning** – The self-questioning strategy involves teaching the student to create questions, predict answers, and search for answers in a text. Self-questioning involves 5 steps: (1) attend to clues as you read; (2) say some questions; (3) keep questions in your mind; (4) identify the answers; (5) talk about the answers. This allows students to actively interact with the text to promote intrinsic motivation by supporting them to identify their own reasons for reading a text.
- **Think-aloud** – The think-aloud strategy involves you (the teacher) modeling thinking aloud as you read a section, discussing how good readers re-read sentences, reads ahead for clarification, and looks for context clues while reading. Develop questions like "What do I know about this topic? What will I learn about this topic?" demonstrate thinking-aloud. This strategy supports students' comprehension and can also be implemented in across subjects (i.e., math, writing).
- **Graphic organizers** – Provide your students with graphic organizers (i.e., story mapping; story element charts; KWL charts) to help them arrange new information to support their understanding of the material
- **Task analytic instruction** – Task analyses break down complex processes/skills into discrete, manageable steps. This strategy can be used to simplify tasks in various domains (i.e., math processes, reading strategies, social skills techniques, classroom organization).

Language

Children with neurofibromatosis type 1 may display difficulties in language. Common language difficulties include deficits in:

Semantic Language

Semantic language involves understanding the meaning of words. Deficits in semantic language can present as: difficulties in asking or answering questions; difficulties following verbal directions; struggles in understanding the relationships between words; difficulty sharing spontaneous information.

Receptive Language

Receptive language involves the ability to understand spoken and written language. Some children with NF1 may display difficulties in receptive language which can be reflected as a child having a limited vocabulary, confusing verb tenses, and reusing certain words among others.

Expressive Language

Children with expressive language difficulties struggle to communication their thoughts using spoken language and sometimes basic written language. Individuals with NF1 may have difficulties with the speech-language and motor processes needed to express and communicate their thoughts to others (e.g., stuttering, articulation of sounds).

Cognitive Concerns

Verbal Working Memory

Verbal working memory refers to the amount of verbal information that a person is able to remember and process. Difficulties with verbal working memory are evident in individuals with dyslexia, ADHD, and/or dyspraxia – common learning disabilities also seen in individuals with NF1. Children with verbal working memory difficulties can have problems such as sorting letter sounds, and putting them all together to get the proper meaning of the right word. They may also struggle with following multi-step instructions or tasks given verbally.

Language Comprehension

Comprehension of language is the ability to correctly process grammar in sentences, word/phrase meanings, and text structure in both written and spoken language. Children with NF1 may display difficulties in language comprehension as a result of overarching issues with processing information.

Teaching Tips & Supports

- **Use concrete teaching methods** – To help students build their vocabulary, you can use concrete items to help them associate the item with the word such as:
  - Picture communication symbols (PCS)
  - Tactile miniature items
- **Modeling** – You can help strengthen your student's language skills by modeling an appropriate verbal exchange.
- **Expansion** – You can expand on your student's responses by using different words that have the same meaning as the word your student used.
- **Repetition** – Repeating instructions and then having your student repeat the instructions aloud will help with both their language skills and memory.
- **Task analytic instruction** – Task analyses break down complex processes/skills into discrete, manageable steps. This strategy can be used to simplify tasks in various domains (i.e., math processes, reading strategies, social skills techniques, classroom organization).
- **Semantic mapping** – Semantic maps are a kind of graphic organizer where students visually show the meaning-based connections between words. This strategy can help students expand their vocabulary and language development.

Teaching Tips & Supports Continued

- **Mnemonics** – Teaching your students to use mnemonics, memory tricks used to hold information, can help alleviate difficulties with their verbal working memory. For example, students can remember the mnemonic "PEMDAS" to recall the order of math operations "parentheses, exponents, multiplication, division, addition, subtraction" or "POWER" to remember the steps in the writing process "Plan, Organize, Write, Edit, Rewrite/review".
- **Self-questioning** – The self-questioning strategy involves teaching the student to create questions, predict answers, and search for answers in a text. Self-questioning involves 5 steps: (1) attend to clues as you read; (2) say some questions; (3) keep questions in your mind; (4) identify the answers; (5) talk about the answers. This allows students to actively interact with the text to promote intrinsic motivation by supporting them to identify their own reasons for reading a text.
- **Think-aloud** – The think-aloud strategy involves you (the teacher) modeling thinking aloud as you read a section, discussing how good readers re-read sentences, reads ahead for clarification, and looks for context clues while reading. Develop questions like "What do I know about this topic? What will I learn about this topic?" demonstrate thinking-aloud. This strategy promotes students' language development by verbalizing what they do/don't understand and in identifying context cues to uncover the meaning of vocabulary words.

Cognitive Concerns

Attention

Children diagnosed with NF1 may also have issues with attention. Although the prevalence of ADHD is much higher in children with NF1 than the general population (30-50%), attention problems can still be evident even without hyperactive tendencies or an ADHD diagnosis. Individuals with NF1 may have trouble paying attention to a particular topic for extended periods of time while other individuals with NF1 can be very attentive to one subject and have trouble shifting to other topics.

Teaching Tips & Supports

- **Breaks** – Allow your student to take breaks when needed
- **Facilitate structure & schedules** – Create and post visual schedules so routines are predictable
- **Limit distractions** – Reduce the amount of distractors in the classroom; have your student clear desk when working on a task
- **Differentiate instruction** – Provide your student with different modes of presentation for assignments (i.e., oral reports; visual presentation; collages)
- **Multi-media approaches** – Using different formats to present information (e.g., text, video, audio, pictures) can help your students better attend to the material
- **Self-monitoring** – When students self-monitor, they identify, monitor, and record whether a target behavior (e.g., remaining on task) has occurred or not. This strategy can help students stay on task, reduce behavior problems, improve academic performance, increase social interactions, and facilitate independence.

Motor Skills

Approximately 1/3 to 1/2 of individuals with NF1 also exhibit motor problems. Many children diagnosed with NF1 have delayed development of motor milestones such as starting to speak or walk. Physical limitations such as skeletal and muscular abnormalities like reduced muscle strength, scoliosis, and pseudoarthrosis can add to the motor difficulties. Motor problems include difficulties with fine and gross motor skills. Fine motor movement issues can present as a child having trouble properly holding a pencil while gross motor movement issues can look like a child being clumsy and bumping into things. Children with NF1 who have motor difficulties often struggle with copying, handwriting, and/or drawing.

Teaching Tips & Supports

- **Motor activities** – Implement activities that engage fine and/or gross motor usage
  - cutting with scissors
  - putting beads or blocks on a string
  - squeezing a stress ball or PlayDoh
- **Motor breaks** – Provide short, frequent motor breaks while modifying movements as needed, such as:
  - dancing along to songs
  - yoga or stretching
- **Speech-to-Text/ Audio recordings** – Allow students to use speech-to-text apps or audio recordings to support note taking and to reduce copying
- **Adaptive pencil grips** – Grips can help students with fine motor difficulties to grasp writing instruments

Behavioral Concerns

Social Skills

Interacting and socializing with others is often very difficult for individuals with NF1 to do. They may struggle forming friendships which can often result in peer rejection. About 5% of children with NF1 are diagnosed with autism, and a considerably higher percentage have some autistic features. Children with NF1 may present deficits in their social skills - socially acceptable behaviors considered important by others. While starting a conversation with a new person you meet might seem like second nature to some, children with NF1 often have a difficult time understanding socially appropriate norms. These social skill deficits may be attributed to problems with visual perception. Children with NF1 may not accurately perceive and interpret social cues like gestures, facial expressions, or tones of voice which can impact social interactions.

Teaching Tips & Supports

- **Peer/Group work** - Facilitate peer and/or group activities and projects to provide opportunities for social engagement with others
- **Peer models** - Pair student with peers who demonstrate strong social skills as models
- **Modeling & role play** - Model appropriate social interactions and allow student to repeat them
- **Social narratives** - Use social narratives (social stories) to describe and explain social norms and/or expectations
- **Behavior specific praise** - Praise the behavior you want your students to display (e.g., "I like how you asked your seat partner about their weekend!")
- **Self-management strategies** - You can teach your students to use self-management interventions to improve their social skills and to increase the number of social interactions. They can self-instruct their behavior (e.g., verbalize "She finished her sentence, I need to ask her a question, I will ask her about her weekend plans"), monitor and record whether the behavior (e.g., initiating a conversation) occurred, then evaluate whether they met their goal (e.g., complete 2 rounds of turn-taking within a conversation with a peer).

Emotions & Behavior

Children and adolescents with NF1 can often experience challenges with their behaviors and emotions. Their mental health may be a concern as children with NF1 commonly experience depression and anxiety, with some struggling with conduct and emotional problems. They can also be hyperactive, impulsive, and inflexible to change. Obsessive behaviors are not uncommon.

Teaching Tips & Supports

- **Breaks** – Provide movement breaks to help with your students' hyperactivity
- **Choice making** – Provide choices/options for students to choose from
- **Schedules** – Use schedules and develop a classroom routine
- **Stress monitoring** – Monitor your student's stress with school assignments and implement tactics to reduce stress (e.g., organize assignments, allow more time)
- **Talk to your class about NF1** – Many students with NF1 can experience depression or anxiety due to social skill difficulties and peer rejection; educate your class on NF1 and promote inclusion

Additional Supports

Students with NF1 may require additional supports and services in order to succeed within the classroom. Students can receive formal educational services through a 504 Plan or an Individualized Educational Program/Plan (IEP).

504 Plan

A 504 Plan protects the rights of students with any kind of disability under Section 504 of the Rehabilitation Act. With a 504 Plan, students are provided accommodations (e.g., extended time on tests, preferential seating, breaks, assistive technology), modifications (e.g., modified grading scale, fewer homework assignments) and/or services (e.g., occupational therapy, physical therapy) to support their success within the classroom.

IEP

An IEP is a formal, written document that articulates the special education instruction, accommodations, modifications, and services that a student will receive under the Individuals with Disabilities Education Act (IDEA). Unlike a 504 Plan, an IEP provides a student with individualized instruction to help the student reach their educational goals in their areas of need. If your student is not progressing academically with the supports provided in a 504 Plan, specialized instruction within an IEP may be needed.

RESOURCES

NF-Related

Children's Tumor Foundation – The Children's Tumor Foundation is a national NF organization that upholds the mission to drive research, expand knowledge, and advance care for the NF community. They offer resources that include brochures and fact sheets on info for educators, info for navigating a new diagnosis, and more.
https://www.ctf.org

NF Network – The NF Network is a non-profit organization founded in 1988 by a group of people who were in some way affected by neurofibromatosis. They are a national organization that advocates for federal funding for NF research and builds/supports NF communities.
https://nfnetwork.org/

National Organization for Rare Diseases – NORD is a non-profit advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.
https://rarediseases.org

Education-Related

Learning Disabilities Association of America – LDA offers supports and resources for educators that includes info on specific learning disabilities, brochures/pamphlets, and best-practice guideline updates.
https://ldaamerica.org

LD Online – LD online provides resources for educators on topics like instructional strategies, evaluation/ testing, IEPs, and accommodations.
http://www.ldonline.org/educators

National Association of Special Education Teachers – NASET is a membership organization that provides support and assistance to those in the special education field. They also provide a report on effective teaching strategies and interventions for students with learning difficulties.
https://www.naset.org/

Council for Exceptional Children – CEC is an international professional organization dedicated towards improving the success of students with disabilities. They set professional practice guidelines and provide tools/resources for educators.
https://exceptionalchildren.org

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