section 4

Executive Function Difficulties in People With Neurofibromatosis

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Many studies have shown executive function deficits in people with neurofibromatosis and in animal models. Although it is unclear exactly why they occur, these deficits are likely related to the developmental impact of the neurofibromin deficit in brain development in people with neurofibromatosis type 1 (NF1). The good news is that early intervention may help people with executive function difficulties.

Executive Function Deficits and Neurofibromatosis

What Are Executive Functions?

The planning and organization necessary to meet daily challenges and create short- and long-term goals require a variety of special skills. Human beings have the ability to pay attention, prioritize, and plan, as well as interpret the feelings of others and respond or behave appropriately, thanks to inherent executive skills commonly referred to as *executive functions*. Executive functions are tasks that require using memory, managing oneself, and prioritizing with set start and stop times.

To perform these executive functions, the brain connects, prioritizes, and integrates cognitive functions moment by moment. This process is performed in key areas of the brain that act as a control center. The frontal lobes of the brain, located in the area directly behind the forehead, control executive function.

These executive functions include the following:



The Importance of Executive Functions at Home and School

Executive functions allow us to perform a multitude of tasks in a variety of environments.

At home and school, executive functions support the following tasks:



Initiation—the ability to start work or a task in a timely fashion



Organization—the design and maintenance of a system to organize items or information



Inhibition—the ability to prevent a reaction and think before acting



Monitoring—judgment of the quality and pace of one's work and behavior



Shift—the movement from one activity to another and flexibility in generating ideas and altering behaviors



Emotional control—the regulation of feelings and reactions to frustration or stress



Working memory—the active, short-term memory used to complete tasks



Flexibility—the revision of plans in the face of obstacles and adaptation to changes



Planning—setting goals and determination of the steps to accomplish them



Time management—the assessment of and assignment of adequate time for an activity

Behavioral Challenges Associated With Executive Function Deficits

If a child is having difficulty with any one of these executive functions, it may become a behavioral challenge.

Some common challenges associated with executive function deficits include

- · failing to think before acting
- not complying with rules
- repeating past mistakes
- being verbally or physically aggressive
- showing concern or sensitivity for others
- needing immediate gratification
- demonstating poor problem-solving skills
- becoming easily frustrated; having difficulty controlling anger
- being disorganized or managing time poorly



Understanding Difficulty With Executive Functions



Time Management

Time management involves the efficient use of time to complete tasks. People who have problems with time management have difficulty estimating how much time they should allow to meet a deadline.



Working Memory

Working memory allows a person to hold information in mind to complete something immediately or in the very short term. People who have problems with working memory have difficulty remembering a series of directions, such as a math problem that involves more than one step.



Organizing Materials

People who have difficulty with organization find it difficult to keep personal items, school supplies, and binders organized so that they can locate things.



Emotional Control

People who lack emotional control often

- become frustrated and lack the coping skills necessary to face adverse conditions
- react emotionally to challenging situations and are less likely to stop and think before speaking and acting
- give up easily and worry excessively
- are overly sensitive
- · feel their emotions come quickly and without warning



Planning Tasks

People who have problems planning tasks often have difficulty

- determining what to do in order to finish a large project
- managing homework, laundry, or bills or sorting priorities and following a to-do list
- reading the instructions for a long-term assignment and managing the steps needed to finish the project on time



Initiating Work

Problems with initiating work can lead to difficulty beginning a task. It can also lead to procrastination, even when the consequences will mean a poor grade or getting in trouble.



Inhibiting Behavior

People who have difficulty inhibiting behavior may find it hard to stop doing something, even if they know they shouldn't be doing it. For example, a child may know that he or she is supposed to wait to speak until called upon by a teacher, but he or she may decide to speak out in class anyway.



Monitoring Tasks

People who have difficulty with monitoring tasks may not understand why they received low grades on a project they thought they did well on. They may also have difficulty rechecking their work or following directions.



Shifting to New Tasks

When a child has difficulty transitioning to new tasks, it may be hard when the teacher asks that an assignment be put away that is unfinished. The child may want to finish it and have a difficult time starting the next assignment.

Key Concepts for Improving Executive Functions

Children with NF1 frequently have problems with tasks that require executive functioning. They may have a hard time organizing materials to complete homework assignments, figuring out how much time a task will take, and setting deadlines. As a rule, it helps to give clear, direct instructions with frequent reassurance and explicit feedback.

Your child cannot improve his or her executive functions alone.

He or she will need your help through the school years and during the transition into adulthood. During this process, try to keep the following things in mind:

- Training is effective
- · Development follows a trajectory: aim for improvement over time
- · Be patient and consider what is age appropriate
- Executive function training is good for everyone, but it requires a lot of practice
- Computer training is available to help with the process



problem solving

Baking Cookies

We use executive functions every day, even in simple tasks around the house. Baking cookies, for example, is an activity that can help improve your child's executive functions. It can help children develop planning, organization, attention, problemsolving skills, visual motor skills, safety skills, body awareness, and fine-motor skills.

Baking cookies includes

- reading a recipe and following directions
- remembering to wear oven mitts to safely put the cookie sheet in the oven
- keeping track of ingredients on the counter or table to avoid knocking them over
- small balls or by spreading it out flat and using cookie cutters adapting and staying calm if you forget

making cookies by rolling dough into

- an ingredient or do a step out of order
- coordinating movement, such as holding a measuring cup in one hand while pouring milk into it with the

Steps

- 1. Plan which ingredients to use
- 2. Calculate the amount needed of each
- 3. Measure them
- 4. Follow written or verbal instructions
- **5.** Be patient (which is to say, have self-control)



problem solving

Cleaning the House

Cleaning the house can also help children with NF1 develop organization problemsolving skills, time-management skills, visual motor skills, body awareness, and fine-motor skills. It is important to motivate your child with a reward for working at and completing the chore.

Steps

- 1. Have your child shadow you on chores that are appropriate for his or her age
- 2. Make sure you show and explain the tools you use (such as a spray bottle)
- **3.** Demonstrate and explain the actions you use ("This is how you scrub."). Use clear directional words ("Move the brush from side to side.")
- **4.** Explain why you are doing what you are doing ("You scrub from side to side to get all of the dirt off.")
- 5. After several demonstration sessions, allow your child to complete the task





activity to share with your child

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setting goals

When Moxie is at school or at home, she needs to always be prepared, and that includes setting goals. In the space below, write down some of your goals.

Now, circle the goal that is most important to you. List the steps that you are going to take to achieve this goal. Be sure to write down any help you may need to achieve this goal. Steps to achieve my goal