



The NF Parent Guidebook

How to Help Children With Learning Challenges
Associated With Neurofibromatosis Type 1

look inside

Meet Our NF Mascots	4
Section 1: The Impact of Neurofibromatosis on the Family.....	5
Section 2: What Is Neurofibromatosis Type 1?	11
Glossary	19
Section 3: Talking With Your Pediatrician	25
Section 4: Executive Function Difficulties in People With Neurofibromatosis	39
Section 5: Strengthening Family Relationships, Part 1	51
Section 6: Strengthening Family Relationships, Part 2.....	63
Section 7: Strengthening Family Relationships, Part 3.....	77
Section 8: Strengthening Family Relationships, Part 4.....	87
Section 9: Social Skills Deficits in Children With NF1	101
Section 10: Building an Education Team: Bridging the Gap Between Home and School ...	109
Section 11: Educational Rights for Your Child, Part 1.....	123
Section 12: Educational Rights for Your Child, Part 2	133
Section 13: Resilience, Transition to Adulthood, and Future Success.....	143
Acknowledgments.....	160

Prepared by Maria T. Acosta, MD, of the Gilbert Family Neurofibromatosis Institute at Children's National Health System. Other contributors: Beth Kaplanek, RN, BSN, and Karin Walsh, PsyD.

This project was initiated and funded by the Children's Tumor Foundation.

Copyright © 2017

meet our NF mascots

Moxie and Sparx are helping the **Children's Tumor Foundation** to end neurofibromatosis (NF). Moxie and Sparx will be your guides as you and your family follow along with the *NF Parent Guidebook*. They will lead you through some fun activities for you to engage in with your child.



Hi, I'm Moxie!

I'm a courageous bear who wants to help you strengthen family relationships. I'm a champion for teamwork and communication. I believe that strong families are at the heart of the NF journey. I want you to remember that you are not alone—you have each other, your healthcare team, and the NF community supporting you!

Hello, I'm Sparx!

I'm a clever, quick-witted fox who wants to spark your love for lifelong learning. I believe that families who take the time to learn about NF are empowered throughout the NF journey. I know that each family is different. That's why it's important to be creative and be patient—you'll discover what works best for you and your family. And remember, don't be afraid to ask questions!

section

1

The Impact of Neurofibromatosis
on the Family

The Impact of Neurofibromatosis on the Family

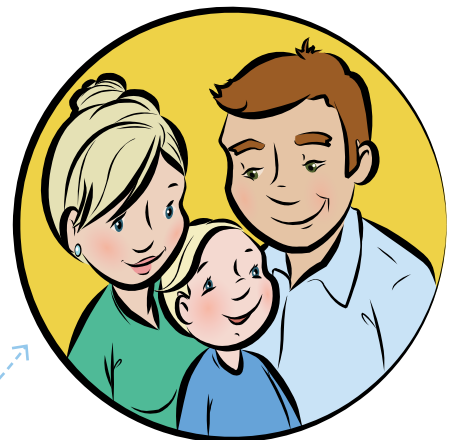
A diagnosis of neurofibromatosis type 1 (NF1) in a child impacts the entire family. It may heighten emotions that can add to the usual challenges of daily living. In addition to the stress that a diagnosis of NF1 brings to families, associated conditions, such as attention deficits, behavioral problems, and difficulties with social interactions, can add more stress and further impact quality of life for the family.

You Are Not Alone: Support and Information to Help You and Your Family

The NF Parent Guidebook: How to Help Children With Learning Challenges Associated With Neurofibromatosis Type 1

It is important that families with NF know that they are not alone. Many families experience these difficulties both immediately and long after the diagnosis. The *NF Parent Guidebook* is a home-based resource designed to provide support and education to families throughout their NF journey. The information the program provides is based on surveys and studies completed by other parents just like you.

The *NF Parent Guidebook* can be completed at your own pace and convenience, and it can be repeated as many times as you would like. The *NF Parent Guidebook* contains useful information and resources to help guide you through your journey with NF and associated learning, behavioral, or social deficits. It is important to understand that The *NF Parent Guidebook* is *not* a tool for diagnosis or a replacement for medical or developmental evaluations. It is a place to find ideas, strategies, and suggestions that will help you understand and meet the needs of your family and child.



family

strategies

Parenting Strategies

After a child has been diagnosed with NF, it is common for the family to feel overwhelmed with stress and emotion. Parents may find it challenging to keep normalcy at home while adjusting to meet their child's needs, such as a schedule filled with doctor's appointments. The affected child's siblings will likely also be impacted and may find it difficult to understand situation.

Here are a few parenting strategies that may help keep you from becoming overwhelmed:

- Learn about your child's diagnosis—knowledge is power!
- Be consistent
 - When possible, share the parenting duties
 - Try to choose your battles and not “sweat the small stuff”
- Understand your children and their individual needs and strengths
- Encourage your family to work as a team
- Develop a routine, as structure can be comforting
- Remember that you are not alone; consider attending support groups
- Above all, try to maintain a sense of humor

Remember that
you are not alone.



strategies

Taking Care of Yourself and Your Relationships

Often, caring for your children seems to leave little time for anything else. It is important to remember that taking care of yourself and your relationship with your significant other are two of the most important things that you can do, for both yourself and your family.

Before getting started, keep in mind the following suggestions:

Learn as much as you can about your child's diagnosis and the issues that you will face together as a family

Try not to take your child's issues personally

Practice compassion, for yourself, for your child, and for your close friends and family

Keep a "disability perspective," to help shape your responses to your children; this perspective means being sensitive to the needs and abilities of your child

Try to remember that parenting is not the cause of your child's difficulties, but it can help lessen the impact of the symptoms

compassion



activity to share with your child

1



Print this
page for
your child!

color me in

Moxie and Sparx are here for you!

Print this page and color it in. When you're done, hang it in a place where you will see it, such as on your refrigerator.



Moxie

Sparx

section

2

What Is Neurofibromatosis Type 1?

What Is Neurofibromatosis Type 1?

We use "NF" to refer to a group of genetic conditions that cause tumors to grow around the nerves. NF includes neurofibromatosis type 1 (NF1), and all types of schwannomatosis (SWN), including *NF2*-related schwannomatosis (*NF2*-SWN). Each of these types of NF is a different condition, and one type does not lead to another type.

Neurofibromatosis type 1 is the most common type of neurofibromatosis. It affects 1 in every 2,500 people born worldwide. The cause of NF1 is a change in a gene. A gene is a sequence of DNA, which is the genetic code that is passed down from parents to children. Because of this, a child can inherit NF1 from a parent who has the disorder. About half of the time, however, a child with NF1 is the only person in the family who has the disorder. In such instances, the NF1 gene change occurred as the result of “spontaneous mutation”—a random error in the process of copying genetic information.

Neurofibromatosis 1 is not the consequence of drug, alcohol, or X-ray exposure, or any other factor under the control of the child’s parents. NF1 is not contagious. Contact between an affected child and an unaffected child cannot transmit the condition.

The NF1 gene is responsible for the production of neurofibromin, a protein that keeps cells from growing too quickly. Without this control, the cells can continue to grow and divide around the nerves, producing the tumors commonly found in NF1.

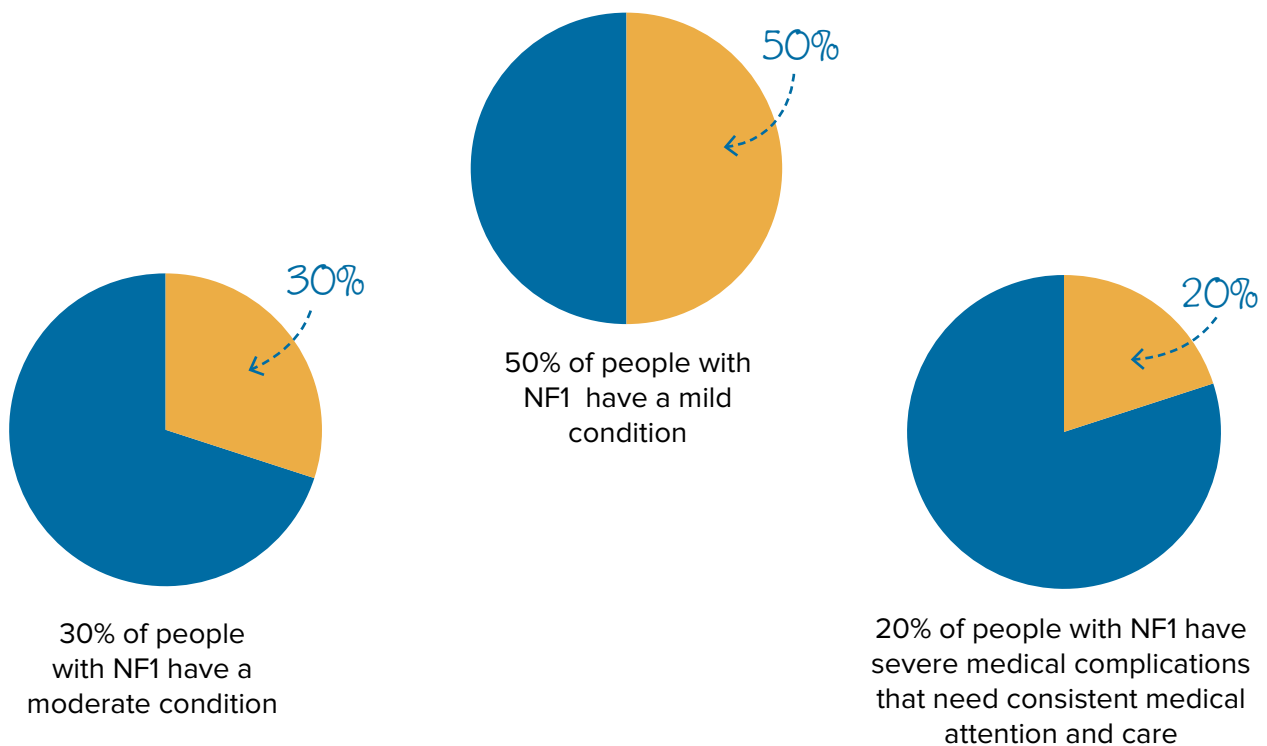
Neurofibromin is also involved in processing nerve signals, including signals inside the brain and those that send messages between the brain and the muscles. That is why problems with neurofibromin affect how the brain receives, processes, stores, and sends information.

It is difficult to predict the progression of symptoms, so it is recommended that people see their doctor regularly. There is still much left to learn about NF1. The medical community is working diligently to gain a full understanding of this condition.

s y m p t o m s

It is difficult to predict the progression of symptoms, so it is recommended that people see their doctor regularly. There is still much left to learn about NF1. The medical community is working diligently to gain a full understanding of this condition.

Although genetically linked, all affected family members may not experience the same symptoms. Both the severity and the symptoms themselves may vary.



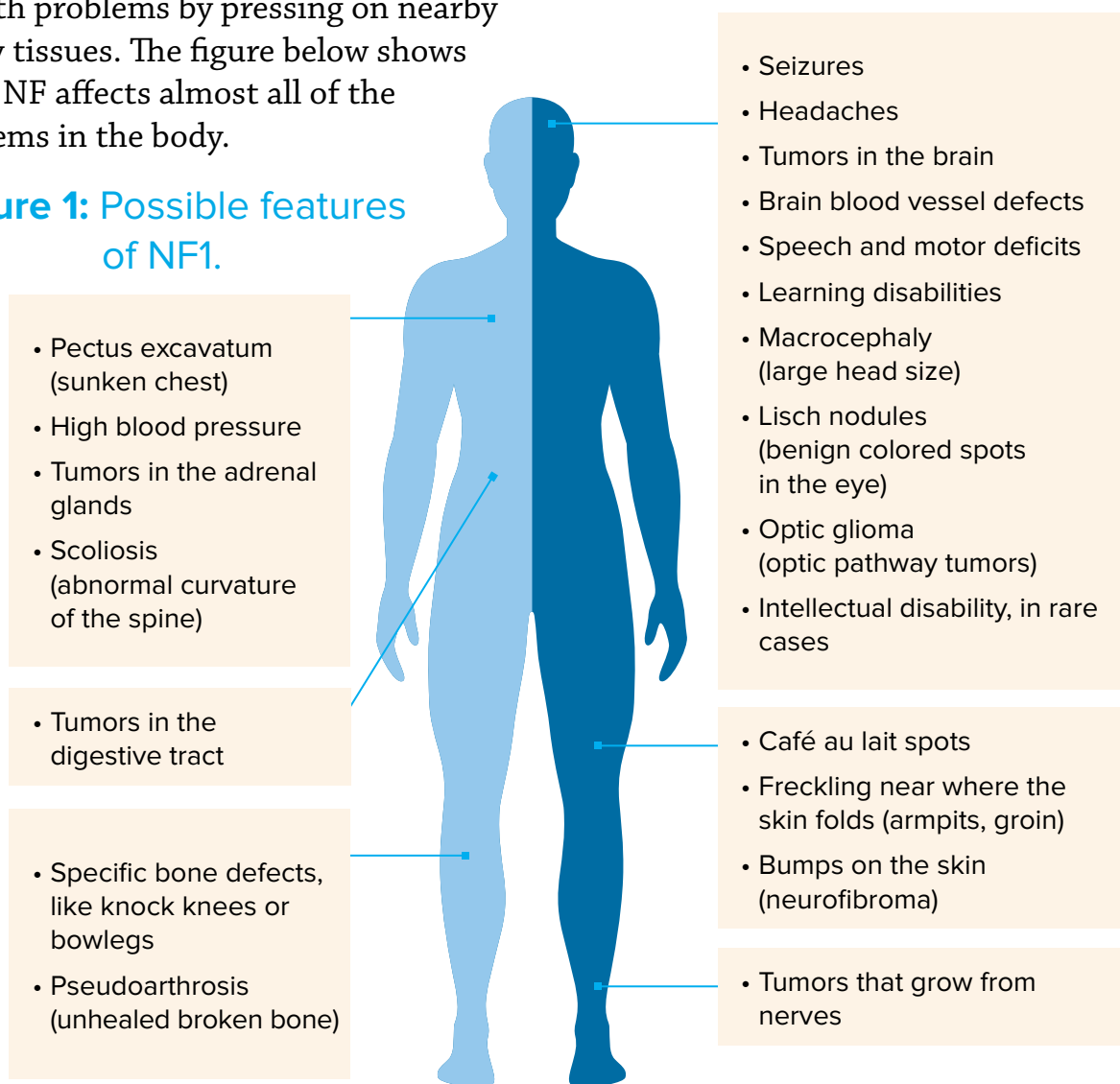
symptoms

Symptoms of NF1

Light brown skin spots called *café au lait* spots and *neurofibromas*, which are small noncancerous tumors that grow on or under the skin, are the most common features of NF1. These tumors can cause health problems by pressing on nearby body tissues. The figure below shows how NF affects almost all of the systems in the body.

For more information about all types of NF and its symptoms, please visit www.ctf.org/education.

Figure 1: Possible features of NF1.



symptoms

Common Symptoms of NF1 at Each Age

The ways that NF affects your child will change as your child grows up. The chart below gives you an idea of medical problems to watch for over the course of your child's lifetime.

Figure 2: Emergence of common symptoms of NF1 at each age.

	Congenital 0 to 2 years	Preschool 2 to 6 years	Late Childhood and Adolescence 6 to 16 years	Adulthood 16+ years
Café au lait spots				
Diffuse plexiform neurofibromas				
Superficial or nodular plexiform neurofibromas				
Tibial dysplasia				
Skinfold freckling				
Optic pathway tumors				
Learning disabilities				
High blood pressure				
Headaches				
Neurofibromas				
Scoliosis				
MPNST				

MPNST = malignant peripheral nerve sheath tumors.

Please see the Glossary at the end of this section for definitions of many of these words.

research

Differences in the Brain

Research has found that in some people with NF1, parts of the brain have a different form and can be “wired” in a different way. Compared to a brain without NF, a brain with NF may have changes in the connections between brain cells called *neurons* and a different amount and distribution of a substance called *neurotransmitters*. A neurotransmitter allows neurons to communicate with one another to transfer information. In doing so, they help regulate a wide range of psychologic and physical functions, including emotion, movement, learning, and memory.

Many proteins are critical to brain development. Neurofibromin is one of these essential proteins. The NF1 gene provides the instructions for making neurofibromin (see “What Is Neurofibromatosis Type 1?” on page 12). Although it is known that neurofibromin is important in the brain development and wiring process before and after birth, it is not understood exactly how. Doctors are currently conducting research to better understand the role of neurofibromin in normal brain development. It is known that early identification of NF1 and subsequent intervention may help with brain development after birth.

These “wiring” and structural differences in the brain can result in a variety of difficulties.

People with NF1 may have challenges in the following areas:



Visual
perception



Language



Motor skills



Attention



Behavior



Executive
function



Social skills

development

Motor and Social Development in Children With NF1

When raising a child with NF1, you may notice some problems with his or her motor development.

These problems can include

- low muscle tone (muscles may feel softer compared with others)
- loss of muscle strength at rest
- mild delay in the development of motor skills
 - walking delayed by 4 to 5 months
- delayed handwriting and pronunciation of speech

There are also some social development obstacles that children and teens with NF1 may face, including



difficulty relating to other children



communication problems



feelings of isolation



difficulty making friends



being bullied



depression



anxiety

learning

Learning and NF1

Difficulty learning can dramatically affect the quality of life of those with NF1. Although the frequency of intellectual disability is low, as many as 90% of children and adults may need some form of learning assistance. Many people with NF1 have difficulty making sense of what is seen (visuoperceptual deficit) and where objects are seen in relation to other objects (visuospatial deficit). It is also common to have trouble with executive functioning skills, which include planning, management, attention, and organization.

8 of every 10 people with NF1 have a moderate to severe impairment in learning.

6 out of every 10 people with NF1 have attention deficit hyperactivity disorder (ADHD) of some type.

5 of every 10 have poor reading, spelling, and mathematic skills.

The most common subtypes of ADHD in people with NF1 are the primarily inattentive or combined subtypes.

glossary

Lisch nodules—well-defined, dome-shaped elevations on the surface of the eye. They range in color from clear yellow to brown.

Neurofibroma—small bumps or growths on or under the skin that are usually not harmful.

Neurofibromin—a protein that keeps cells from growing too quickly.

Macrocephaly—a condition in which the head is abnormally large.

Optic glioma—a brain tumor that forms in or around the optic nerve, which connects the eye to the brain. As the tumor grows, it presses on the optic nerve, affecting vision.

Pectus excavatum—a condition in which the rib cage forms abnormally and the breastbone (sternum) caves in. The condition is also known as sunken chest or funnel chest.

Plexiform neurofibroma—a tumor that tends to involve large nerves. Sometimes, they form under the skin or deeper, but they can also involve small nerves and form on the surface of the skin (superficial). Though they are usually not cancerous, these tumors may grow and affect the structure of nearby bone, skin, and muscle. There are two main types of plexiform neurofibromas: diffuse and nodular.

- **Diffuse:** If these tumors are described as diffuse, it means there is usually no clear point, or edges, of where the tumors begin or end. These tumors also appear to spread out like fingers
- **Nodular:** If these tumors are described as nodular, it means they look like small clusters, or nodules, along the nerve

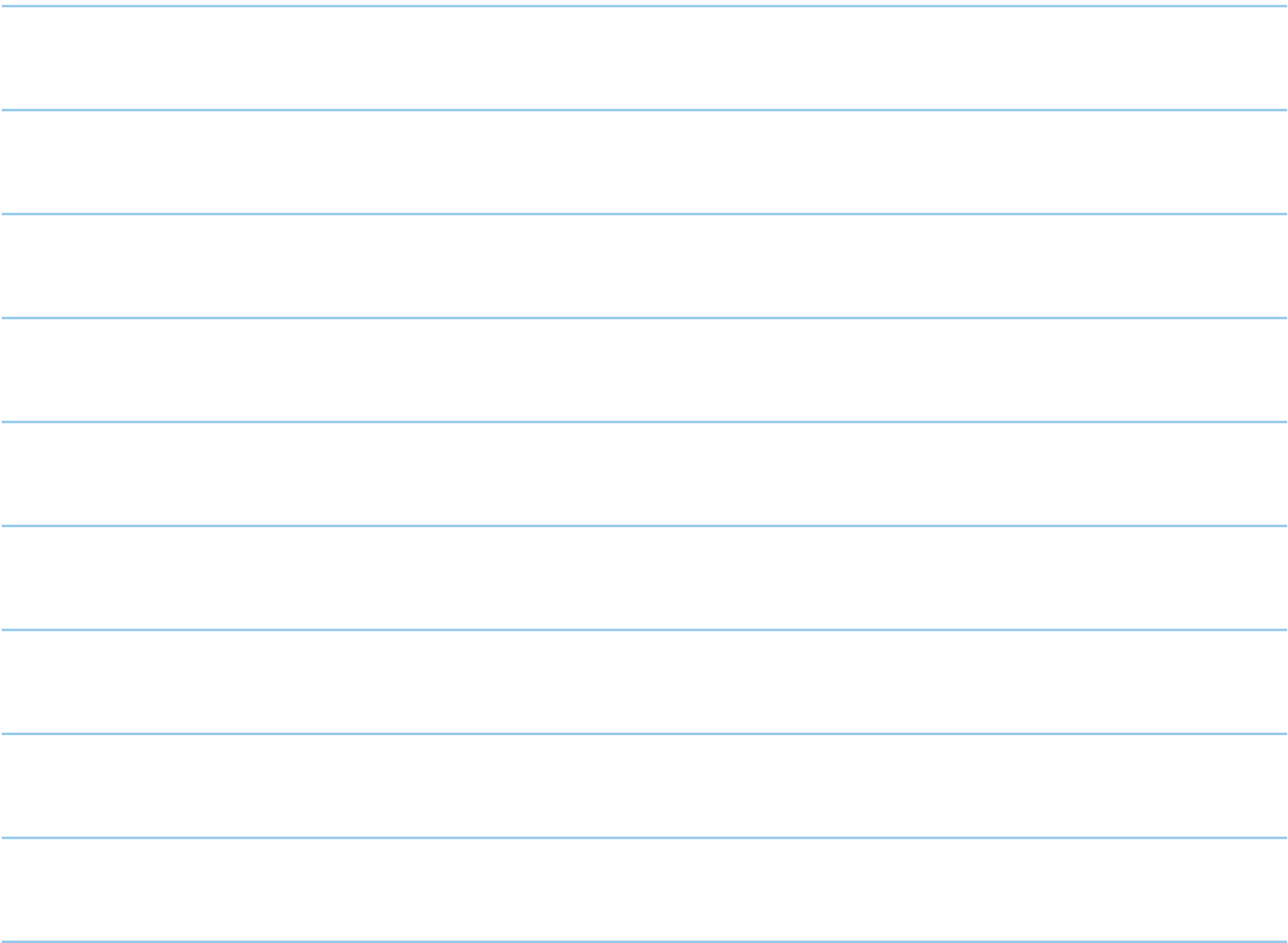
Pseudoarthrosis—a break in a bone that does not heal on its own.

Scoliosis—a condition in which the spine curves abnormally.

Tibial dysplasia—a condition in which the shin bone (tibia) curves or bows excessively.



notes





activity to share with your child

2



Print this
page for
your child!

word search

Help Sparx find the words in the list below.
Circle all the words you can find in the puzzle.

Word list

- ☐ Neurofibromatosis
- ☐ Chromosomes
- ☐ Cells
- ☐ Genetic
- ☐ Family
- ☐ History
- ☐ Severe
- ☐ Evaluations
- ☐ Learning
- ☐ Brain
- ☐ NF
- ☐ Neurofibromin
- ☐ Symptoms

I	O	C	H	R	O	M	O	S	O	M	E	S	B	H	J	U
I	A	O	G	X	O	V	R	G	K	Y	W	R	J	B	G	X
Z	M	I	E	E	N	T	S	F	E	R	A	C	E	X	Q	I
U	P	F	N	N	E	U	R	O	F	I	B	R	O	M	I	N
F	J	Y	E	O	M	H	G	G	N	V	G	B	L	X	T	B
C	Q	S	T	E	V	A	L	U	A	T	I	O	N	S	K	F
B	L	E	I	L	E	A	R	N	I	N	G	B	Y	X	A	P
V	H	E	C	S	M	R	V	U	C	N	Q	V	O	M	I	T
C	E	L	L	S	E	Q	G	U	U	J	U	F	I	J	F	W
G	O	T	G	P	E	V	V	K	R	W	K	L	H	Z	N	T
M	K	A	V	P	W	V	E	S	E	G	Y	I	F	H	E	C
N	E	U	R	O	F	I	B	R	O	M	A	T	O	S	I	S
Y	S	G	S	E	S	A	M	M	E	C	A	B	Q	I	O	X
B	G	U	H	W	C	L	N	P	H	C	I	S	L	I	U	S
Y	V	V	E	F	R	P	R	J	G	H	I	S	T	O	R	Y
H	W	O	C	R	Y	H	T	M	L	M	X	J	T	J	J	Z
I	S	Y	M	P	T	O	M	S	Y	J	G	C	B	J	Z	W

The answer key to this puzzle is on the next page.

Hint! Search across, down, diagonal, and backward!

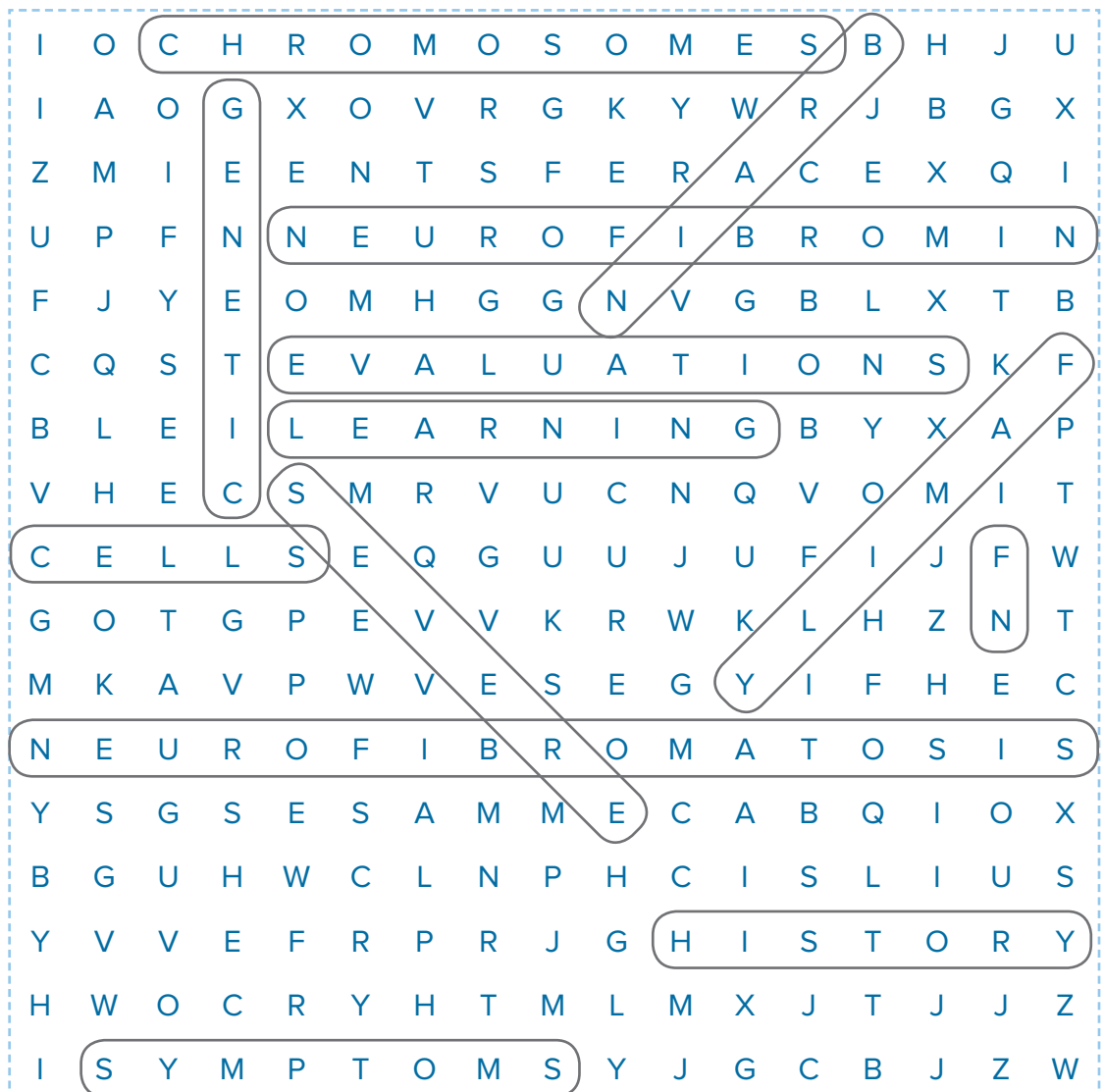


word search

Answer Key

Word list

- ☒ Neurofibromatosis
- ☒ Chromosomes
- ☒ Cells
- ☒ Genetic
- ☒ Family
- ☒ History
- ☒ Severe
- ☒ Evaluations
- ☒ Learning
- ☒ Brain
- ☒ NF
- ☒ Neurofibromin
- ☒ Symptoms



notes

section

3

Talking With Your Pediatrician

Talking With Your Pediatrician

As your child grows, you will watch as he or she achieves many developmental milestones. It's important to talk with your child's pediatrician if you believe that your child's development may be delayed.

For example, you may notice that your child is not walking or speaking as expected or that he or she has difficulty focusing.

Your pediatrician can observe your child and help determine whether medical problems are impacting your child's development and whether further evaluation is necessary.



You Play an Important Role in Your Child's Care

It is unlikely that anyone else knows your child as well as you do. Your pediatrician will need your help in understanding your child's strengths and challenges. Your physician may ask you a series of questions or provide a questionnaire for you to complete.

You can also help your child by collecting information from all caregivers and educators who spend time with your child to gain a complete understanding of his or her performance in a wide array of functions. If any of this information or insight worries you, share your concerns with your pediatrician or care provider.

You are your child's most important advocate.

Visit ctf.org/education to download or request brochures that you can share with your child's pediatrician, teachers, and other caregivers.

evaluations

Evaluations to Help Understand Your Child

There are many useful evaluations available to help your pediatrician and health care team understand your child's abilities. This section will outline the evaluations commonly used to assess the development of cognitive, motor, and language skills in children with neurofibromatosis type 1 (NF1). If you have any questions about these evaluations, or about your child's eligibility to take them, talk with your pediatrician or child care provider; he or she can direct you to resources that are available in your area to answer your questions.

Developmental Evaluation

Pediatricians conduct developmental evaluations for all children during an exam, even during well visits. In this evaluation, the pediatrician reviews your child's progress in reaching expected developmental milestones. The pediatrician uses standard measurements that compare your child's acquisition of developmental milestones according to a specific age range. The pediatrician observes a broad spectrum of skills that are expected to develop, including your child's fine-motor abilities, language, and ability to perform age-specific independent functions.



milestones



Print this page!

evaluations

Surveillance

During all visits, the pediatrician should provide developmental surveillance, an important technique used to observe and collect information about your child. This is the first step toward deciding whether further evaluation is necessary and to rule out any other medical problems that may be impacting development. During surveillance, your pediatrician will ask you a series of questions. He or she may also give you questionnaires to complete at home or in the office before the visit.

Here are a few example questions:

- How is your child doing in school?
- Does your child have problems with learning?
- Are you concerned about any behavioral problems at home or school or when your child is playing with friends?
- Is your child having problems completing class work or homework?

The pediatrician may collect additional input from your child's other caregivers, such as your child's teachers at school. It's important to share your concerns with your child's other health care providers and caregivers. If there are any problems, the pediatrician can recommend that further assessment be conducted.

Use this space to write down concerns to share with your pediatrician.

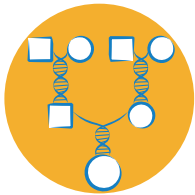


evaluations

Assessment for Learning and Behavioral Problems

A more in-depth assessment can be performed by one of your child's primary care providers, which may include your pediatrician or nurse practitioner. Specialist providers, including developmental pediatricians, neurologists, psychologists/neuropsychologists, and others, can provide more extensive evaluation of your child's development, including the identification of behavioral or learning problems.

A comprehensive assessment may include



a detailed family
and mental
health history



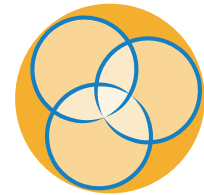
observations
and/or
interviews



a physical
exam



a behavioral
rating scale



an evaluation
for coexisting
conditions

Psychoeducational Evaluations

A psychoeducational evaluation is a school-based assessment that focuses on your child's ability to perform in relationship to the academic curriculum by age and grade. This evaluation may vary from school to school, but it is typically designed to assess for the presence of a learning disability that interferes with the child's functioning within the academic setting. A psychologist will perform this evaluation. Results from this evaluation will help you and the members of your child's educational team determine an appropriate academic path for your child.

It's important that you understand your child's educational rights and ask for additional testing as needed.

evaluations

Different assessment procedures, or a combination of procedures, are used to examine the following individual areas of performance and concern:

Cognitive skills



IQ testing

Achievement



academic skills

Communication skills



verbal and
nonverbal

Behavioral
development



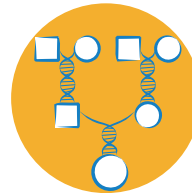
rating scales and
observations

Psychosocial
development



psychological and
social adjustment

Family history



developmental
history

Although cognitive deficits may impact your child's educational success, these challenges are part of the broader medical concerns associated with NF.

evaluations

Neuropsychological Assessment

A neuropsychological assessment is a specialized, comprehensive evaluation performed by a neuropsychologist that provides information on how the brain is affecting behavior and learning. The results provide information on your child's strengths and weaknesses in the areas of reasoning, memory, and problem solving. This form of evaluation utilizes direct testing of your child's learning and cognitive skills as well as symptom questionnaires provided by parents and teachers, behavioral observations, and in-depth clinical interviews.

In a neuropsychological assessment, the individual areas of performance and concern include

- verbal and nonverbal reasoning (intelligence)
- attention
- executive functions, including short-term and working memory, flexibility, impulse control, self-starting, strategic planning, and organization
- visual and verbal memory
- visual-motor and spatial abilities
- language and communication
- social-emotional development

You are an expert in your
child's individual needs.



evaluations

Evaluation Interpretation and Follow-up

After receiving the results from your child's evaluations, review them as a whole and ask for clarity if needed.

Use this information to

- maximize your child's strengths to address his or her difficulties by sharing this information with school and family members
- be an *active* member/participant of the your child's academic team. Participate in the development of accommodations and interventions for your child to address his or her needs
- talk to your child, and help him or her to understand why certain tasks may come easily and why some things may be more difficult

When a newly instituted education plan is in place, follow up with members of your child's educational team in about three months to see how your child is performing on the new plan.

interventions

Advocate for Your Child

All evaluations are useful, but not all may be deemed necessary by your child's school when considering your child's academic performance and developmental level. That is why it's important to become an expert in your child's individual needs. Talk to your child's school about your child's problems and then decide, as a team, on a plan of action for meeting his or her needs.

After the Results: Types of Intervention

The primary goal of obtaining any of the evaluations described above is to help your child's health care and educational team develop a custom plan to help your child with his or her individual needs. Different types of interventions are available and recommended for different situations.

Depending upon your child's results, he or she may benefit from either or both of the following types of interventions:



Home-based intervention

Behavior programs, some using technology, that help address cognitive and psychological/behavioral difficulties within the home.



School-based interventions

Special education plans such as a Section 504 Plan or an Individualized Education Program (IEP) may be recommended to assist with academic and social problems within the school setting. These school-based interventions will be discussed in more detail in section 11.

interventions

What Is Early Intervention?

Early intervention (EI) is a home-based intervention program for children younger than school age. Although a child is often referred to EI by his or her pediatrician, a parent or caregiver can also ask for an evaluation for EI services. Most states offer evaluations and services free of charge.

Early intervention programs are designed to address delays in early motor, language, and behavioral development.

Early intervention can include



speech
therapy



occupational
therapy



physical
therapy



behavioral
interventions

It is important to set up at-home prevention strategies, too, which can be as simple as talking to, playing with, and smiling at your child often.

You may also consider setting up a special play time that incorporates fine-motor activity skills, such as



playing with
Play-Doh®



painting



drawing



assembling or
building items

It's important that you do not wait for a problem to occur
start an intervention early!



interventions

“I am beautiful.

I am not my disease. I am powerful...I am a fighter!”

—Candice Patterson, who lives with NF

All of this information may seem a bit overwhelming, but it can be helpful to think positively, focus on one or two challenges at a time, and remember that change takes time.

Here are a few tips for starting your EI:

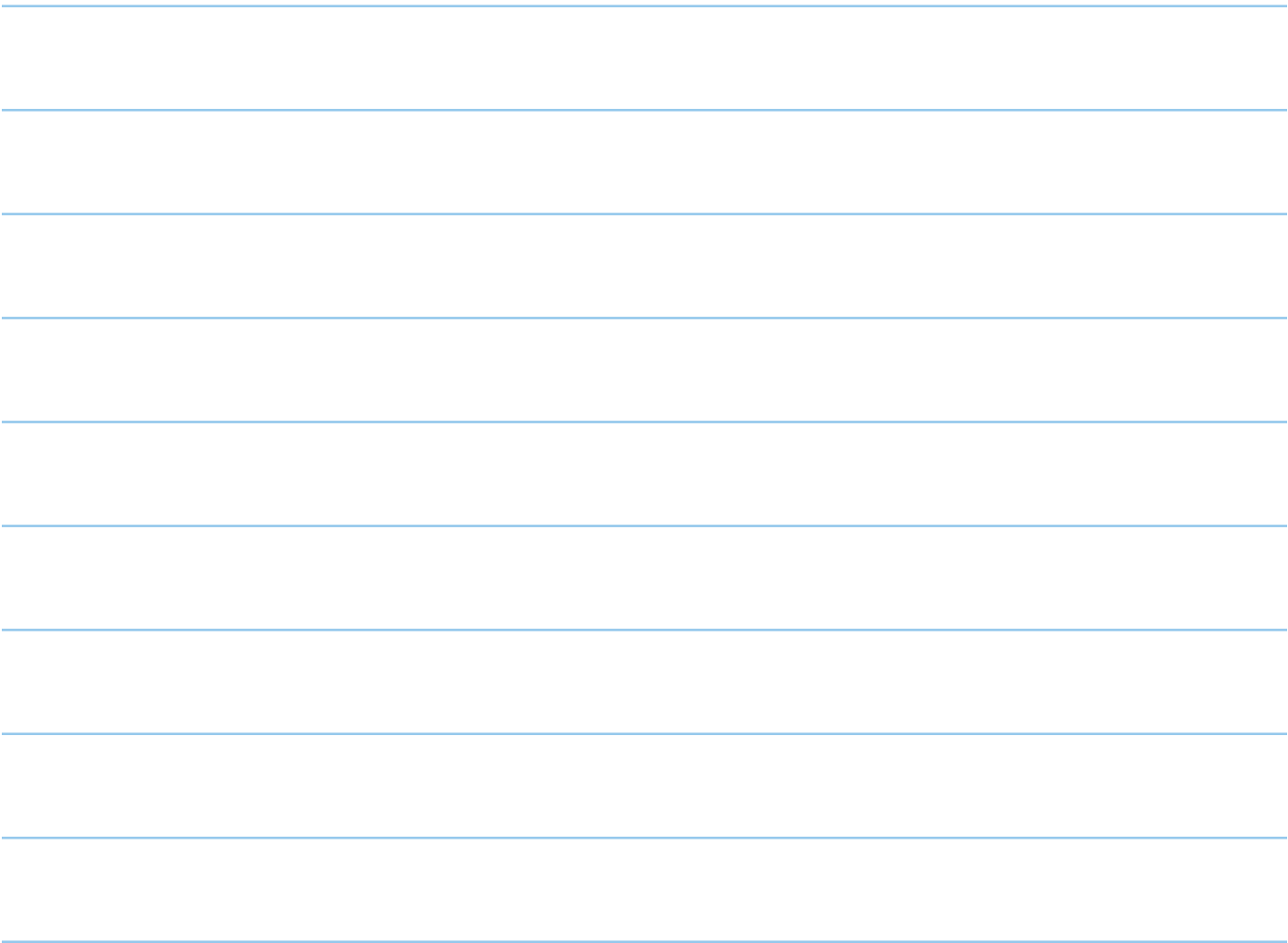
- Recognize that you can only work on things that are within your control
- Do not try to work on all of your child’s deficits at once—tackle one challenge at a time
- To help you decide which challenges to tackle first, pinpoint those challenges that affect your child and family the most
- Try interventions that others have found useful
- Try strategies that maximize improvement with low effort
- Look for available tools and technologies that can help



Together you will make it through.



notes





activity to share with your child

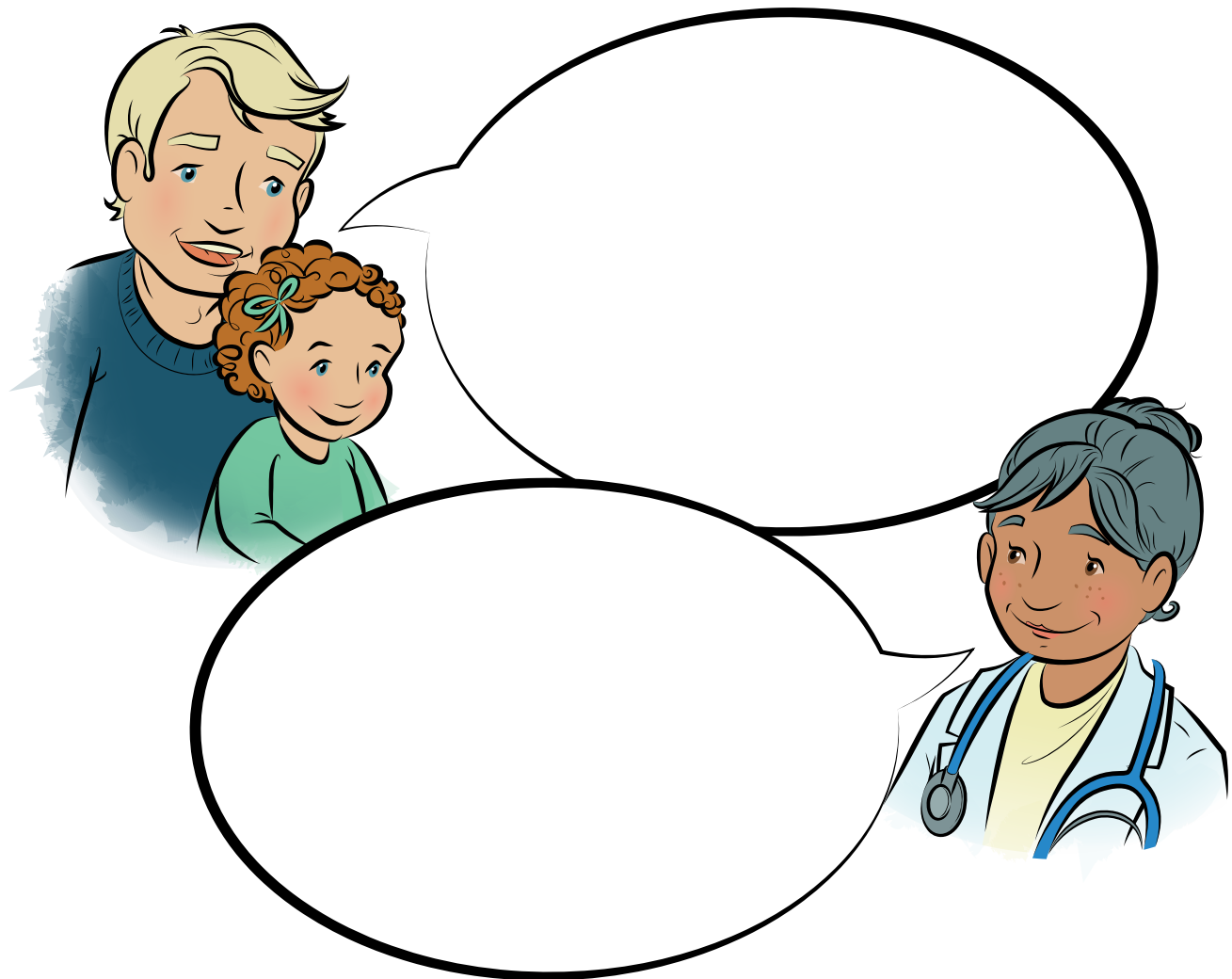
3



Print this
page for
your child!

ask a question

Sparx knows that it's important to talk to your doctor. In the bubble at the left, write a question that you would like to ask your doctor, and at the right, ask your parent or guardian to write in your doctor's answer.



section

4

Executive Function Difficulties in People
With Neurofibromatosis

Executive Function Difficulties in People With Neurofibromatosis

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:



executive functions

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

executive functions

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
- demonstrating poor problem-solving skills
- becoming easily frustrated; having difficulty controlling anger
- being disorganized or managing time poorly



executive functions

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.

executive functions



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.

executive functions



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.

executive functions

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

practice

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, problem-solving 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
- making cookies by rolling dough into small balls or by spreading it out flat and using cookie cutters
- adapting and staying calm if you forget 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 other hand

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 problem-solving 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

4



Print this
page for
your child!

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



section

5

Strengthening Family Relationships
Part 1

Strengthening Family Relationships

part one

What to Expect From a Child With Neurofibromatosis

Children with neurofibromatosis (NF) have a legitimate medical condition that can change their ability to learn and regulate their behavior. It is important for parents to set realistic expectations that consider their child's disability and age.

Children with NF

- can improve their behavior with the assistance of effective parenting strategies and interventions
- should be expected to make gradual rather than rapid behavior progress
- will respond more favorably to supportive and positive discipline strategies than to rejecting or punitive discipline strategies
- have the same need and desire as other children to gain acceptance from others

Internal Versus External Control

Deficits in executive functioning can undermine a child's ability to use *internal* control to regulate behavior, as he or she can lack an internal management system.

Because of this lack of internal control, the behavior of children with executive function deficits is more *externally* controlled. This makes an external management system very helpful in most cases. Behavior can be controlled by the conditions of a child's environment and by the development of an immediate reward system.

strategies

Two Management Strategies for Behavior Problems

There are many different types of strategies for helping parents manage their child's behavioral issues. Two of the primary management strategies are called *proactive* and *reactive*. A parent can consider both strategies and select the one that might prove most effective for his or her child.

Proactive Strategies: To Prevent a Behavior

- Proactive interventions are set before the behavior occurs
- These interventions are designed to reduce the occurrence of bad behavior

Reactive Strategies: To Respond to a Behavior

- Reactive interventions are implemented after the behavior occurs
- These interventions use rewards to encourage good behavior or consequences to discourage bad behavior

proactive
reactive

house rules

Proactive Strategies: House Rules

Above all, setting up clear daily routines is one of the first and best proactive strategies for managing behavior problems. The structure created by a routine provides comfort to a child with executive function deficits, helping to reduce stress and keep emotions in control. For routines to be effective, it is important to establish house rules that every member of the family follows.

House rules provide clear behavioral expectations for the child and help to

- ☒ set and clarify behavioral limits and/or boundaries
- ☒ emphasize the importance of specific parental expectations
- ☒ make sure that there is consensus in the family about the house rules

The following tips can help you institute house rules and guidelines to support your child's behavior:

- Hold a family meeting to “brainstorm” a list of potential house rules
- Select three to five rules from the list to be the house rules
- Establish rewards and consequences for compliance or violation of the rules
- Post the rules on charts that can be easily read
- Remember to explain the rules to the child
- Each week, target a rule for emphasis
- Highlight or circle the rules on the chart and pay added attention to compliance with or violations of this rule
- Each night, review examples of instances in which your child complied with or violated a rule

State the house rules in specific, objective language

For example,



do not say,
“Be responsible”



say,
“Put your dishes in the dishwasher”

tips and tools

Helping Your Child to Develop Organizational Strategies

To follow certain rules, such as keeping his or her bedroom clean, your child may need help in understanding how to tackle the task.

Here are a few tips to help you help your child:

Designate a spot
for every item



Have a permanent spot for your child's backpack, wallet or purse, phone, and planner, and check these items every evening before bed



Label bins and drawers



Set up a closet system with hooks

Schedule clean-up



- Photograph the expected results
- Decide the frequency and timing with your teen
- Give reminders of when the clean-up day is approaching

Link room clean-up to privileges.



Print this
page for
your child!

tips and tools

Here Is an Idea! Try a Chore Card

Cleaning up Your Bedroom

Check off the chores you complete.



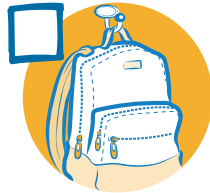
Pick up your toys
and place them on
the toy shelf



Pick up dirty
clothes and
put them in
the hamper



Place your
shoes on the
shoe rack in
the closet



Place your
backpack on the
backpack hook



Group your school
papers on the
desk into piles



Straighten the
covers on the bed



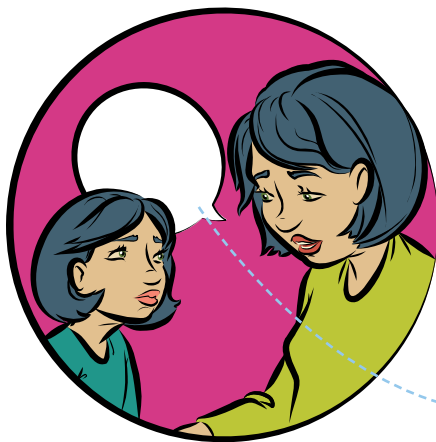
Take wet towels to
the bathroom and
hang them on the
towel hook

time management

Helping Your Child to Develop Time Management Strategies

Here are a few tips and tricks that you can use to help your child enhance his or her time management skills:

- Establish daily routines, and consider making simple check-off cards or charts for routines that are repetitive, such as cleaning the bedroom or getting ready for school in the morning
- Schedule chores for older children with a set time for completion
- Give notice and time frames



My car leaves at 7:00 AM.
If you want a ride to school
instead of riding the bus, be at
the door at 6:55 AM.

- Create a daily reminder list with time frames and sticky notes
- Use timers, watches, and visual aids to teach time management
- Place a large at-a-glance calendar in a noticeable place
 - Work actively with your child to get into the habit of planning ahead



Print this
page for
your child!

strategies

- Incorporate your child's participation in the preparation of family plans, such as a family vacation, so that he or she gets used to seeing how the logistics of outings come together
- Embrace the use of a written planner for school and personal use
 - Example: the planner could be issued by the school, computer generated, or an electronic device

Example for a younger child:

	1 Get out of bed when the alarm goes off		5 Go to the school bag hook by the back door to put on your shoes
	2 Put on clothes that are laid out		6 Get your backpack off the hook for school
	3 Come to breakfast when Mom calls		7 Leave for school
	4 Brush your teeth		

strategies

Example for an older child:

Develop a schedule for completing a task

Working backward from the completion date, mark the milestones on a calendar that outline the steps needed to complete the a project, such as writing a report for school.



notes



activity to share with your child

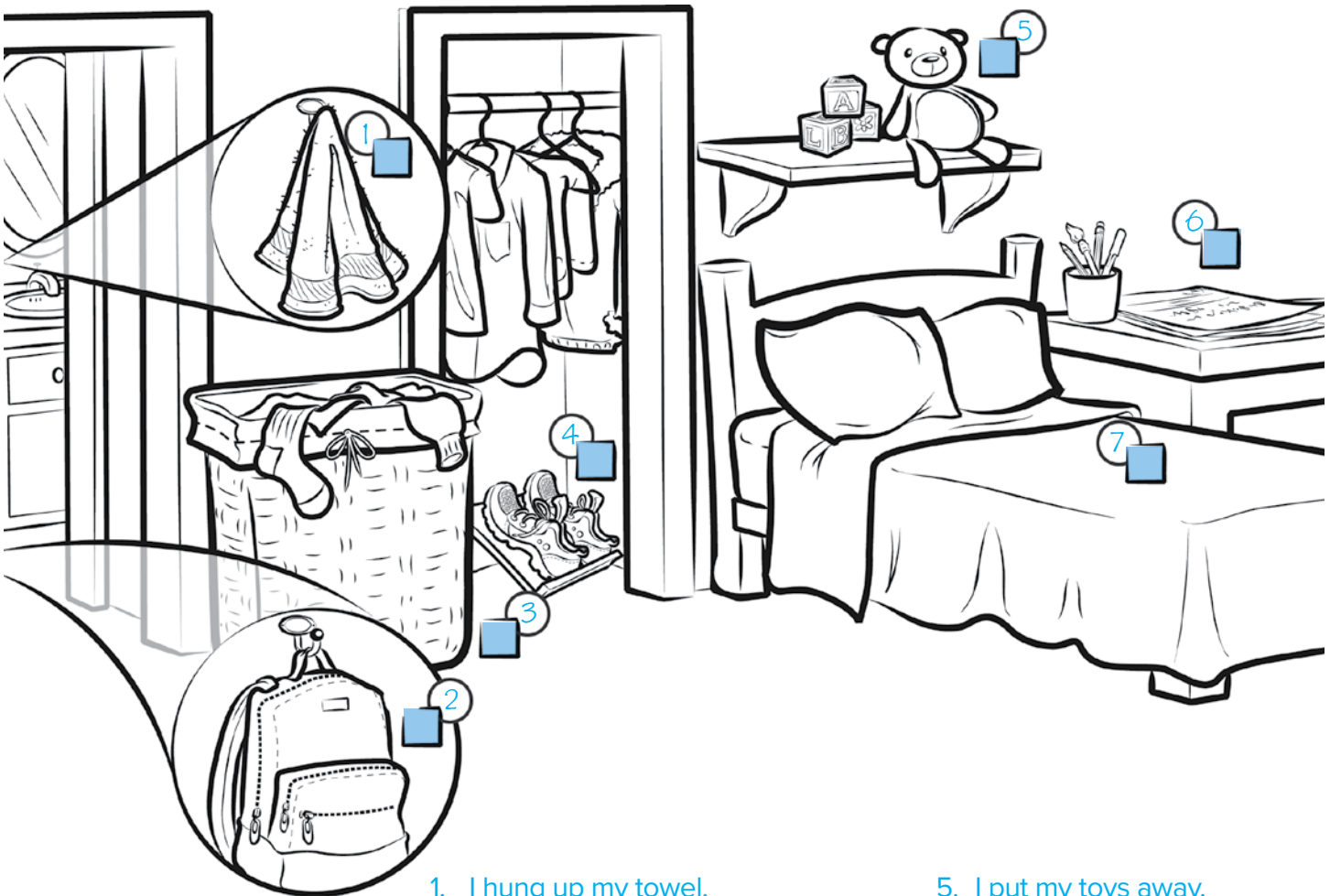
5



Print this
page for
your child!

tidy up your room

Moxie likes keeping her room clean, and so should you.
Keep this checklist in your room in a place where you will see it.
Use it to make sure that your room is clean every day.



1. I hung up my towel.
2. I put my backpack in its place.
3. I put my dirty clothes in the hamper.
4. I put my shoes away.
5. I put my toys away.
6. I tidied up my school papers.
7. I made my bed.

section

6

Strengthening Family Relationships
Part 2

Strengthening Family Relationships

part two

Reactive Strategies

Improving the behavior of your child can be challenging. Children need their parents to provide not only the directions but also the feedback that keeps them on a good behavior path.

Reactive strategies

- are evidence-based
- reinforce good behavior with positive motivation (such as rewards) and discourage bad behavior with negative motivation (such as consequences)
- work by applying consequences *after* a behavior has happened

Reinforcement (Reward) Guidelines

.....

Programs don't just work on their own—to get the most value out of them, it's important to execute them with consistent follow-through.

Here are a few guidelines:

- **Immediacy:** Reinforce good behavior with a reward as soon as it happens
- **Frequency:** Use positive reinforcement often to encourage repetition of good behavior
- **Novelty:** Keep your child's interest high in the type of reinforcement (ie, don't do the same thing for too long)
- **Enthusiasm:** Talk to your child about the importance of good behavior
- **Description:** Make sure your child understands the connection between his or her behavior and the consequences that follow



rewards

Limitations of Rewards

.....

Reward programs have a few limitations that are important to keep in mind:

- Behavioral changes are generally gradual rather than dramatic
- Improvement in behaviors *may* not continue or “stick” after you stop giving rewards
- Rewards do not directly weaken the bad behavior

Also, it’s important to understand a reward program is not likely to be effective if the *reason* for your child’s negative behavior is stronger than the reward he or she receives for performing good behavior. Also, if the chosen reward or reinforcer is not something your child will work for, it will not be effective. Sometimes it takes time to find the most effective reward, and this can change over time.

Benefits of Rewards

.....

When executed well, reward programs may help improve behavior and benefit your child in other ways.

Reward programs can do the following:

- Sustain motivation and effort during low-interest tasks
- Highlight the cause-and-effect link between good behavior and positive outcomes (reward)
- Direct your child’s attention to the outcome of a behavior
- Enhance your child’s sense of competency
- Foster a positive parent–child relationship
- Build up the strength of good habits

r e w a r d s

Three Types of Reinforcement (Rewards)

There are **three common types of rewards** for reinforcing good behavior:

Edible
rewards



such as your child's
favorite treats or dinner

Material
rewards



such as toys, CDs,
video games, or
clothing

Activities or
privileges



such as playing a
board game, wrestling
time with Dad, bike
ride with parents

The parent-child bond is very important to the success of your reinforcement program. **Consider reinforcing good behavior with special one-on-one play time or family activities.**

Studies show that the most powerful
reward for children is time spent
with you!



tokens

Token Economies

A token economy is one of the most effective reactive strategies. The focus of a token economy is to reinforce good behavior as soon as it happens. The token is a symbol of positive reinforcement that your child

- **earns** each time he or she shows good behavior, and
- **exchanges** for a more “valuable” reward when he or she collects a certain number of them

Tokens don’t need to cost money. The reward comes from your child saving them up and exchanging them for something that does have value to them, such as treats, toys, or activities.

Types of Tokens

To be most effective, a token economy program should use tokens that keep your child’s interest and motivation high.

Here are a few suggestions for tokens:



Stickers



Dot-to-dot
charts



Magic Grid



Tangible objects,
such as game
chips

positive reinforcement



t o k e n s

Ten Steps to Designing a Token Program

- 1 Select one specific behavior to target
 - Do not say, “Clean your room”
 - Instead, say, “Put your dirty clothes in the clothes basket”
- 2 Model the behavior for your child
- 3 Select the tokens (or chart) to be used
- 4 Select the reinforcement to be used
- 5 Determine how many tokens must be acquired to earn reinforcement
- 6 Determine the period during which the behavior will be monitored
- 7 Put the terms of the program in writing
- 8 Display the terms where you both can see them
- 9 Start the token program and monitor progress
- 10 Identify obstacles to progress and make adjustments in the program as necessary

When designing your token program, here are a few things to consider:

- Begin with a modest goal
- Target a behavior that you believe will be easy for your child to change
- Start slowly
- Give reinforcement a chance to work
- Be fair

be fair

t o k e n s

Benefits of a Token Program

A token program can be particularly effective in helping to change a child's behavior, because the expectation for the child's behavior is very clear. In this program, children receive the incentive needed to sustain their efforts and make a lasting behavioral change. Tokens can also serve as a visual reminder of the moment when a child made a positive change in his or her behavior, and moving forward will link that behavior and the subsequent reward.

Advanced Token Programs

Advanced token programs can be used to target more than one behavior at a time or break a complex behavior into smaller, sequential steps.

For example, performing homework might be divided into 4 separate behaviors:

Recording the homework	Bringing appropriate materials home
Completing the homework	Turning the homework in to the teacher

By using an advanced token program, a child is reinforced for each step of a complex behavior to help him or her learn how to approach multistep behaviors in the future. Typically, beginning with a token program and moving on to an advanced token program to tackle more complex behaviors is recommended.

tokens

Evaluating the Success of the Program

Parents sometimes incorrectly decide that the token program is ineffective when it is actually providing benefits.

Try to keep these considerations in mind when determining the effectiveness of your program:

- Progress is often gradual rather than rapid
- Consider asking yourself the following questions:
 - Is the behavior occurring less often?
 - Is the behavior lasting for a shorter duration?
 - Is the behavior less intense or severe than before?



progress



free-response cost

An Alternative to a Standard Token Economy: Free-Response Cost

In a free-response cost program, the tokens are freely given to the child at the beginning of the program. A free-response program can be more effective than a traditional token economy when you are attempting to reduce the rate of high-frequency inappropriate behaviors.

Designing a Free-Response Cost Program

You can easily design a free-response cost program in a few simple steps. First, determine the inappropriate behavior and how often it occurs within a certain period. Next, choose a number of tokens to give to your child according to how often the behavior occurs and decide when and how long the behavior will be monitored. Each time the inappropriate behavior occurs, take a token away. If your child has at least one token remaining at the end of the session, he or she will receive a reward.

The loss of a token can be less frustrating because the child is not losing something that was previously earned. The tokens provide a firm, visible boundary, and the program is easy to design, develop, and implement in public settings.

reward

free-response cost

Free-Response Cost in Public Places

Free-response cost is particularly useful in public locations such as restaurants, malls, grocery stores, classrooms, and during car trips. Listed below are a few examples showing how free-response cost can be used in a public setting.

Example 1

John is a 7-year-old child who misbehaves at the grocery store.

- John's mother explains the rules of conduct while at the store
- John's mother provides him with 4 tokens
- John loses 1 token for each rule violation
- If John has at least one token remaining when his mother is finished shopping, he earns a milkshake

Example 2

Carol acts out whenever her parents take her for a long ride in the car.

- Carol's parents explain the rules of the road
- Carol is provided with 3 tokens for a 15-minute ride
- One token is taken away from Carol for each rule violation in the 15-minute period
- If Carol has at least one token remaining at the end of the ride, she earns 30 minutes of extra screen time

reward systems

When Each Reward System Is Most Beneficial

Token Economies

Advantages

- Behavioral expectations are clearly stated
- The child receives frequent reinforcement to sustain effort
- Tokens cue appropriate behavior
- Tokens link the appropriate behavior with the outcome
- Token economies can be used for complex behaviors that must be broken down into smaller tasks
- Reduced frustration while learning a new skill with a feeling of progress and success

Limitations

- Require more time and effort to design and implement
- Require more care to make the program not too complex
- Require more planning, modeling and monitoring

Free-Response Cost Programs

Advantages

- Easy to design and implement
- May easily be used in public places
- Quick way to reduce high-frequency inappropriate behaviors
- Provide a specific and visible behavioral boundary

Limitations

- Do not teach or reinforce appropriate behavior
- Loss of token may frustrate some children

notes



activity to share with your child

6



Sparx loves getting tokens. Help him by circling only your favorite tokens.



section

7

Strengthening Family Relationships
Part 3

Strengthening Family Relationships

part three

Building the Relationship

Building a positive relationship with your child is one of the most important parenting goals. Structure and routine at home, along with clear expectations and sustained house rules, are important to the creation and continuation of that relationship. Together you can teach your child organizational skills, how to follow commands and directions, and encourage problem solving. Reaching a sense of accomplishment together will be a wonderful experience for you both.

Rules – Relationship =

Rebellion

Rules + Relationship =

Success

relationships

Developing Empathy

Empathy is a vital skill for successful relationships. Help your child put himself or herself in another's shoes and see the world through his or her eyes. Try to model this behavior by acknowledging and accepting your child's feelings:

- Avoid telling your child how he or she should feel or attempt to solve a problem when he or she is emotional, because it could create feelings of anxiety and lead to increased frustration
- Instead, use reflective listening strategies to make sure your child feels heard and understood

Reflective listening guidelines

1. Listen quietly and attentively
2. Acknowledge your child's feelings with a word
3. Give the feeling a name
4. You can give your child his or her wishes in a fantasy
5. Be gentle but firm when responding

Here is an example of reflective listening:

Child

"Nobody wants to play with me."

"I am never going back to that school."

"That would be awesome!"

Parent

"It hurts your feelings to think no one will play with you?"

"I bet you wish that school was more fun and easy."

"I wish I could make school more fun for you, but let's think about what other fun things we can do together. Maybe we can bring those ideas to school to have fun."



communication

Managing Conflicts With Effective Communication

Using behavioral intervention techniques such as the token economy can help minimize behavior problems and prevent conflict. Some conflicts, however, are inevitable. Effective communication strategies can help to control the intensity of these conflicts.

Try to provide your child with frequent feedback to help him or her stay on the right behavioral path. If given correctly, praise and constructive criticism can be used positively. For example, praise and thank him or her for putting a glass on the counter. Set a goal of **“filling up their praise bucket,”** making emotional deposits so that your child may avoid reaching emotional bankruptcy.

Praise the behavior you want to see, and be specific. For example, you could say, **“You worked very hard on your science project last night before bed. I’m proud of you,”** or **“Thank you for coming home by your curfew. I didn’t have to wait up and worry.”**

While it is also important to provide feedback and instruction for specific behaviors you do not want to see, be sure to avoid criticizing the child. For example, do not say, “Stop using bad words when talking to me, you are a very difficult child to deal with.” Instead, try, **“That word hurts me. Stop talking to me using bad words.”**

It is also helpful if you mention what behavior you would like to occur next time.

Thank you.
I'm proud of you.
Good job!



Remember to

Be concise

Be short and to the point.

Be sincere and calm

Avoid displaying too much emotion.

Stay in the present

Don't dredge up past mistakes.



communication

Forming Effective Commands

Forming a command the correct way is critical to teaching children to behave. There are three basic steps to forming effective commands.

First, make sure the command is specific. Telling a child to clean a room may lead to him or her to feel overwhelmed and not sure where to begin. Instead, give the child a specific instruction, such as “Put your dirty clothes in the laundry basket.” Try to keep the command short, and avoid multiple instructions within a single command. It is also important to state the command as a statement and not a question. Do not ask the child to do something, tell him or her what to do.

Second, clearly explain the consequence of noncompliance with the command, and provide that consequence immediately should the command not be followed.

Third, reward compliance with the command. This can be as simple as saying, “Great job!” or “I appreciate it.” Children need, appreciate, and respond to positive reinforcement.

Be sure to

- give commands only when you have the time and patience to obtain compliance
- be in proximity to your child when giving the command
- have your child’s attention when giving a command
- not waste time justifying the command to your child

Sometimes parents can make mistakes that teach their child to be noncompliant. Some of these mistakes include giving too many daily commands or failing to follow through with a consequence or reward. It can also be difficult for a child to follow a single command that is stated in many different ways or that isn’t consistent.

self-control

Positive Timeout

Positive timeout is a great technique to help a child learn self-control. The purpose of timeout is not punishment but to give the child an opportunity to regain control of his or her emotions and then rejoin the regular activity.

To begin establishing a timeout, **select a good spot.** A chair, cushion, or beanbag that is separated but not isolated is a good choice. You want to give the child the separation that he or she needs to calm down and refocus, but you also need to remain aware of what is going on around him or her.

Talk with your child in advance about how you will use the “take-a-break” place. Introduce and explain the concept of being calm and regaining control. Explain that it is not a punishment but an opportunity to calm down.

Emotions cannot be controlled,
but reactions can be controlled.



self-control

Intervene as soon you notice the child is losing control; do not wait too long. When a timeout is warranted, it's important that you

- make sure the length of the timeout is appropriate to your child's age. A good rule-of-thumb is to assign 1 minute per year of your child's age (for example, a 3-year-old would get a 3-minute timeout)
- tell your child to go to the take-a-break place to regain control
- say when he or she can come back
- be gentle, use a calm, quiet voice and few words
- do not allow negotiation
- give positive reinforcement such as hugs or kisses, or a "Good job!" once the timeout is over

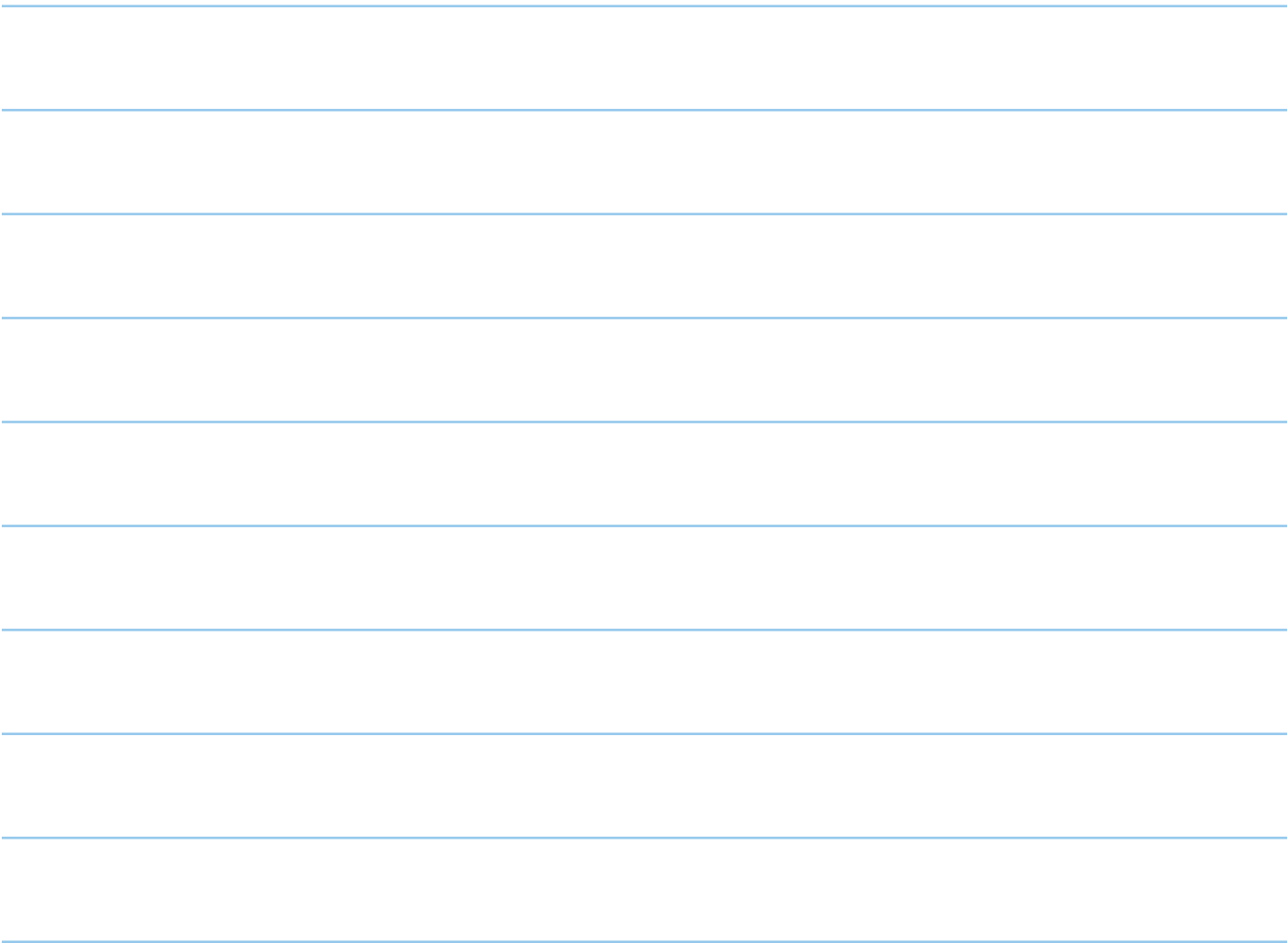
Be sure to

- not overuse timeout, or else it will lose its effectiveness
- use timeout primarily with children of elementary school age
- stay calm, even if your child is not, during timeout





notes





activity to share with your child

7



Print this
page for
your child!

time for dessert

Moxie and Sparx did the dishes without being asked. As a reward, they were told that they could have dessert. Color in all the desserts and circle the one that you like best.



section

8

Strengthening Family Relationships
Part 4

Strengthening Family Relationships

part four

Developing Parenting Strategies and Positive Behavior Interventions

You may have heard the expression “to push someone’s buttons.” Everyone has certain topics, issues, or “triggers” to which they are sensitive. When someone is pushing your buttons, that means he or she is doing something that provokes a strong reaction.

It’s common in many families for parents and children to push each other’s buttons, especially during conflict, when emotions and stress are high. But knowing how to remain calm and avoid communication pitfalls during times of conflict are the key to strengthening family relationships.

Avoiding Communication Pitfalls

When communicating with one another, family members can make many mistakes that can damage relationships. We call these mistakes “communication pitfalls.” Making an effort to avoid these common pitfalls may help to enhance family relationships. When speaking with your child about a problem, keep in mind the following tips:

Describe the problem by giving information relevant to the present problem.

- Avoid blaming, accusing, or dredging up the past. For example, if your child forgets to put the milk back in the refrigerator, you can say “Milk turns sour when it is left out of the fridge” rather than “You’re wasting milk all the time”
- Be specific
- Use 10 words or fewer

communication

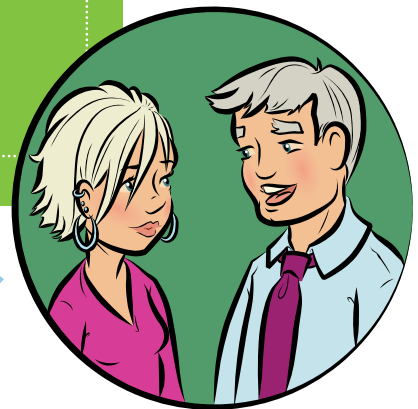
Describe how you feel about the problem.

- Be aware of your tone and expression. How you relay the information can often be directly related to your child's ability to understand it
- Use "I" statements when expressing feelings or providing feedback about a problem
- Be direct and confident when expressing your feelings about the problem—don't be "wishy-washy"

Address problems when you are both calm.

- Try to delay communicating or making decisions about consequences until you and your child have calmed down
- Pay attention to when your child seems most open to talk
- Consider writing a note to express your feelings or expectations if that is easier

The calmer the parent, the more meaningful the consequence.



be direct

buttons

Why Kids Attempt to Push Your Buttons

Children push buttons in an effort to try to have a sense of control or to get his or her parent's attention. Parents must be aware of that and be prepared. Parents can have just as many buttons as their children do, which can cause a defensive reaction when dealing with an emotional child. Understanding your own buttons can help to decrease conflicts. If you also identify your children's buttons and avoid them, you will decrease conflicts.

Here are some of the common ways that your child or teen may use to push your buttons:

- Using bad words

- Making you feel guilty

Example: "If you really loved me, you'd let me go to the party"

- Making personal attacks

Example: "I don't know why I even speak to you. You're too stupid to understand"

- Using fear

Example: "You never let me do anything. Someday, I'm going to kill myself"

- Making you feel like you don't have control

Example: "You can't tell me what to do. I'm not a kid anymore. You're not my real dad. You can't boss me around"

- Appealing to your personal insecurities

Example: "You didn't even graduate from college. What do you know about getting a good job?"

buttons

Identifying Your Child's or Teen's Buttons

Parents often unknowingly escalate conflicts with their children by pushing their buttons. Parents who can identify their child's sensitive areas can avoid unnecessary conflicts.

Here are some common buttons for children and teenagers:



Lecturing: This changes the focus from a child's concerns to the parent's



Talking in chapters: This phrase describes a parent's tendency to talk too much or overexplain when a short response could suffice. For example, a parent might use an example or experience from his or her own childhood to make a point to the child. While a parent vents his or her personal frustration, it may stir up a child's frustration



Expressing intolerance of a child's rebellious behavior and preferences: The child may become defensive in response to a parent's concern for his or her hair style, clothing, or taste in music, for example



Threatening a child with his or her future: This is called "future shock"

buttons

Common buttons for children and teenagers (continued)



Dredging up the past: This condemns a child for past mistakes



Labeling: Calling a child lazy, irresponsible, and inconsiderate, for example, inhibits and discourages further communication



Questioning or probing: It's important that you understand and convey the difference between questioning and interrogation. Questioning places a child "on trial"



Problem solving: It's better to solve problems after the child has had time to deal with unpleasant and hurt feelings. Recognize when the child needs emotional support and reflective listening. The child is more likely to accept responsibility for his or her actions and look at a problem objectively if the child believes that a parent is caring and understands his or her feelings

buttons

When Buttons Get Pushed

Button pushing is inevitable. When a child attempts it, be aware and have some strategies ready to defuse the situation.

- Be aware of the signs of low frustration tolerance. Signals that occur before a meltdown may include
 - facial expressions, verbal comments
 - physical expressions or gestures
 - mood changes
 - increased heart rate
 - flushed face
- Stay calm, do not engage
- Take a time-out
 - Let the child walk away and go to his or her “safe space,” such as a bedroom



damage control

Damage Control: Mending Fences

After a conflict, try to restore the relationship with your child as quickly as possible to prevent lingering resentments.

- Demonstrate your affection as soon as you can in person or in writing
- Use humor to break the tension
- Use distraction to help your child move on
- Go somewhere fun
- Practice compassion

Parents: Make a Plan to Keep Your Cool

When you are yelling at each other, no one is working on a positive solution. The real incident is no longer the focus, and it takes much longer to recover emotionally. When yelling starts, the communication stops.



Print this
page!

keep cool

Here are some tips to help you keep your cool when you feel that your buttons are being pushed. Print this page out and keep it in a place where you will see it, such as on the refrigerator.

- **Stop and stay calm**

- Prepare a rehearsed response; for example: “I’ll get back to you on this later”

- **State your point and walk away**

- Keep it short and to the point; for example: “That’s the rule!”

- **Walk away**

- Tell the child, “I have to calm down,” or have your partner take over

- **Avoid telling your child that he or she is wrong**

- Instead, state “there is a disagreement that must be resolved”

- **If you are uncertain about how you want to respond to the problem, buy time**

- “I’m not sure what is best. Give me an hour to think about this”

- **Reassure your child**

- “If you listen to me, I promise to listen to you”

- **Just describe the problem**

- “The garage door was left open”

- **Use enforceable statements**

- “I will take you to the movies when you clear the table”

- **Say it with a written note**

- “Please remember to clean your closet”

- **Say it with one word or phrase**

- “Cat box” or “dishes”

- **Explain your feelings**

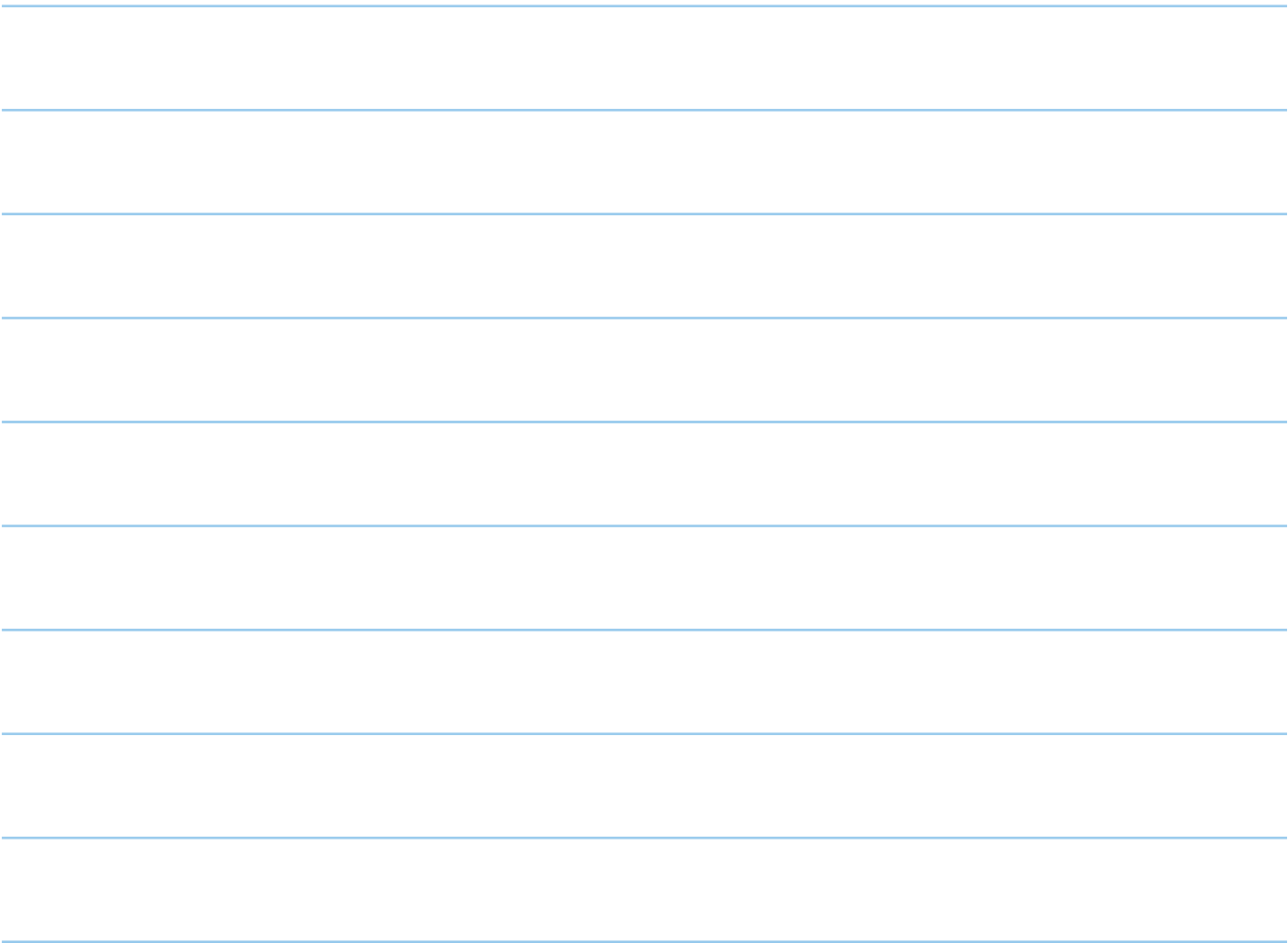
- “It makes me feel like you don’t respect me when you act like that”
- “I love you too much to argue about that”

- **Apologize**

- Set up an apology system for all
- If you do explode, be sure to apologize later



notes





activity to share with your child

8



Print this
page for
your child!

pitfall puzzle

Every family has problems once in a while,
but being able to communicate and work together
to solve problems is what makes families strong.

In the puzzle below, Moxie needs your help to create a path to
effective communication! Connect the dots that represent good ways to
respond if someone is pushing your buttons.
Be sure to avoid the communication pitfalls!



Asking the
other person
to just listen
to me

"You're stupid"

"This is
your fault"

Talking when
I have calmed
down

"You can't tell
me what to do"

Writing down
my feelings
and sharing
them when
I'm calm



The answer key to this puzzle is on the next page.

pitfall puzzle

Answer Key



Asking the other person to just listen to me

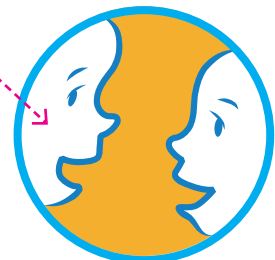
"You're stupid"

"This is your fault"

Talking when I have calmed down

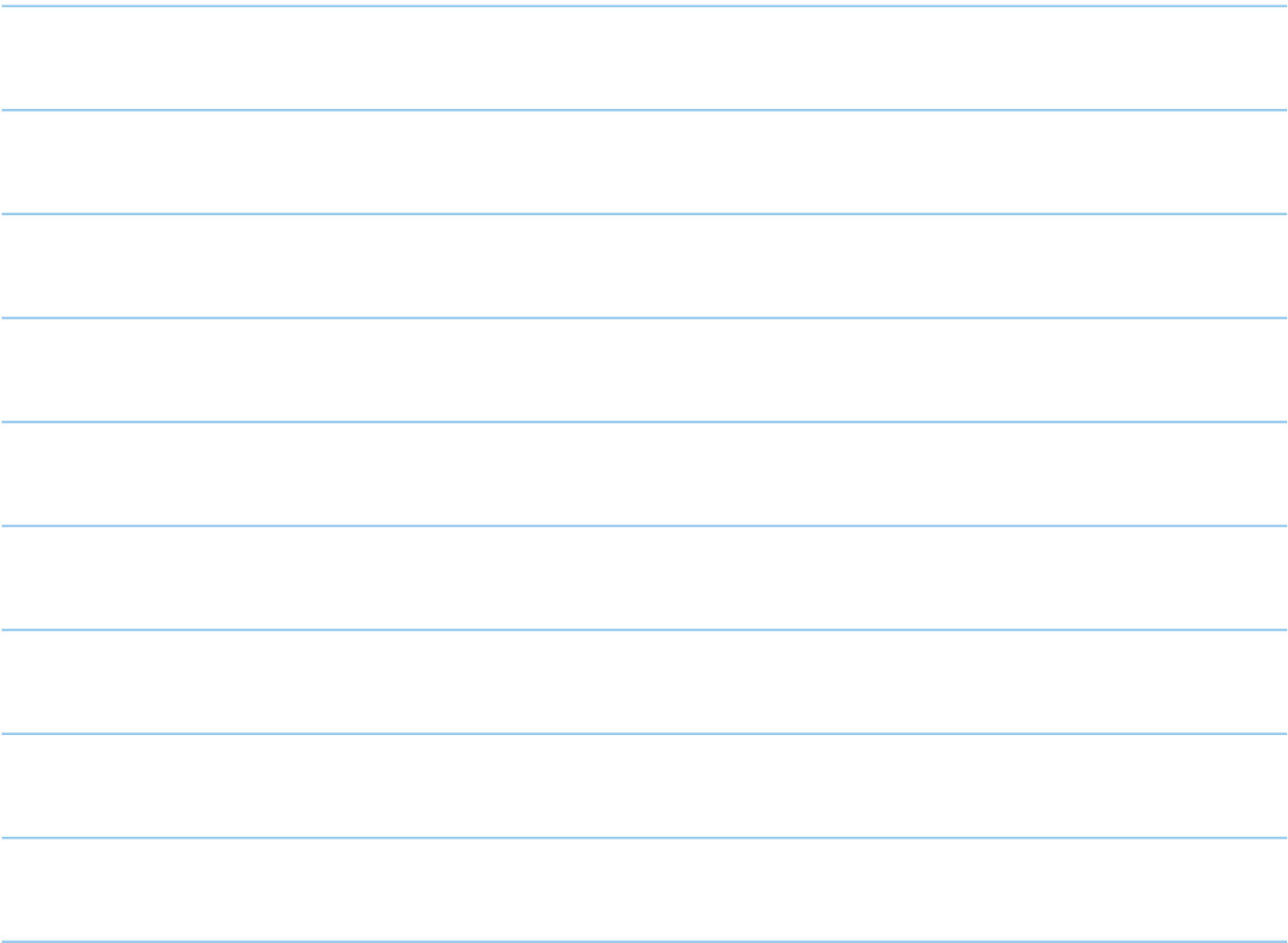
"You can't tell me what to do"

Writing down my feelings and sharing them when I'm calm





notes



section

9

Social Skills Deficits in
Children With NF1

What Is Social Cognition?

Happiness in humans is strongly related to our social interaction. Our ability to have healthy social interactions is determined by our social cognition. Social cognition is the way in which we form impressions of ourselves and others and how these impressions influence our relationships. We use social cognition skills to determine the causes of behavior, both our own and that of others, and relate behavior to social rules.

Social cognition also dictates how our goals, feelings, and desires influence our interpretation and memory of our actions and social events. Our social cognition capacity is shaped by a combination of biological and environmental interactions (genetics, personality traits, culture, social groups, and family styles, among others).

What We Know About Social Interaction Skills in Children With NF1

Parents and teachers alike recognize that children with neurofibromatosis type 1 (NF1) may have problems with social interaction and making and keeping friends. These children often prefer to interact with older or younger children than with children of their own age, as their peers may find them to be socially immature. This difficulty with social interaction can significantly impact a child's quality of life.

Several researchers have reported that NF1 is highly associated with autistic traits and symptoms of attention deficit hyperactivity disorder (ADHD). Social interaction deficits are common in children with ADHD and autism spectrum disorder.



social interaction

Do We Know What the Problem Is?

The exact cause of these social interaction deficits is unknown. A combination of deficits in executive function skills, such as cognitive flexibility, impulse control, and shifting attention, may be an important part. Intense anxiety can also increase the number and severity of social interaction deficits.

Scientists and doctors still have a lot to learn about the exact relationship between NF1 and social interaction difficulties. Information from parents like you is invaluable to their research and interpretation. Talk to your doctor about your observations and let them know what you believe are your child's biggest social challenges.

What Treatment Is Available?

The following pages provide an overview of some of the most common treatment options for social interaction deficits. Some of these options may work better for some children than for others.

treatments
are available

social interaction

Social Skills Support Groups

Pros

- These groups may help affected children become aware of their problems in social interaction situations and “prepare” for the next time they face similar situations

Cons

- Social interaction situations are unpredictable
- There is no guarantee that the situations encountered in therapy will be replicable in real-life encounters

Parent Education and Training

Pros

- Parents can learn how to intervene and help their children in social situations
- Exposure to support will last longer than social skills groups
- Parents can observe real-life situations and provide feedback in real time

Cons

- Parents’ social interaction perceptions can be very different from those of a child’s peers
- Parental intervention may impact parent–child relations
- Children tend to behave in front of adults differently from how they behave in front of other children

social interaction

Medications

- For some patients, management of associated problems such as ADHD, anxiety, obsessive-compulsive disorder, or depression may improve their social interaction
- Ask your doctor for more information

Friendship Coaching

Friendship coaching involves organized one-on-one interactions with an adult serving as an observer without interfering.

Pros

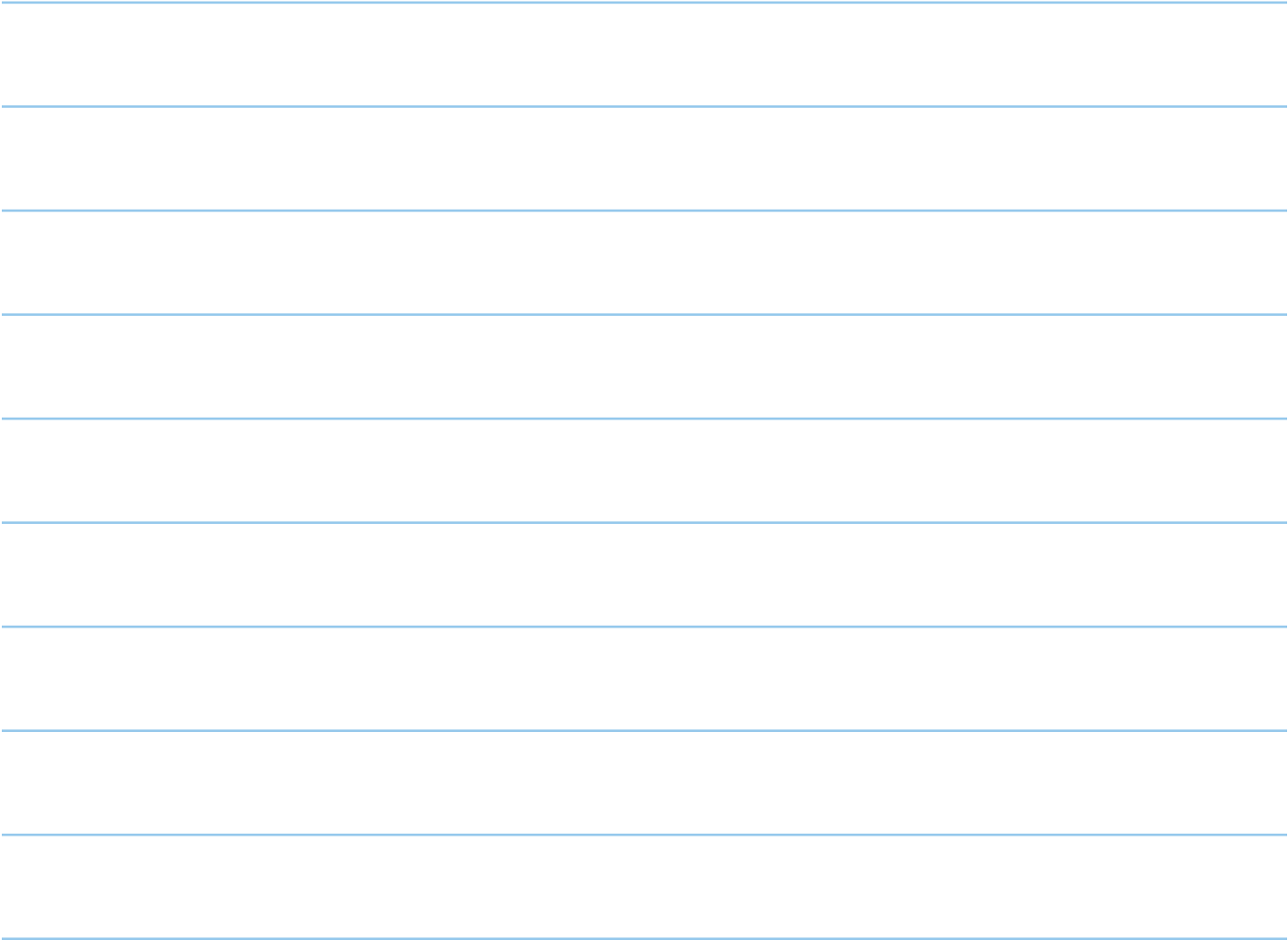
- It allows identification of real-life problems
- It is accessible and available as an in-home intervention

Cons

- Friendship coaching requires that parents, caregivers, or adults in charge of the program understand the process and maintain an objective view of the problem
- It may not replicate group interaction
- Results vary widely



notes





activity to share with your child

9



Print this
page for
your child!

conversation starters

There's always room for new friends!

But how do you make them? Saying hello, smiling, and being friendly is a great place to start. The next step is starting a conversation with someone. One of the easiest ways to start a conversation with someone new is to talk about your interests and to ask that person questions about his or her interests.

Sparx has made a list of questions below to help you start a conversation. Write down your responses. Then, choose a few of your favorite questions to ask someone new.

What is your favorite thing to do when you're not in school?

What's your favorite subject in school?

Are you in any team sports or clubs?

What do you want to be when you grow up?

What is the funniest thing you ever saw?

What is the best thing about you?

What is your favorite book or movie?

What is your favorite food?

What kind of music do you like?

If you could go anywhere in the world, where would you go?



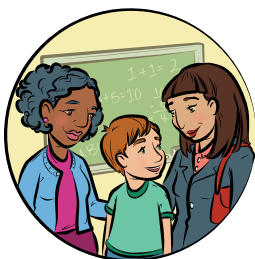
section

10

**Building an Education Team:
Bridging the Gap Between Home and School**

Working Together: Parent-Teacher Communication

Parents and teachers need to work together to meet their common goal of making a child's education successful. It is important that teachers and parents understand how to support one another to meet this goal.



Parents need teachers to

- explain their expectations and assignments clearly
- monitor each child's daily performance
- provide feedback
- be sensitive and responsive to a child's struggles with homework
- be flexible in addressing the accommodations or modifications a child may need

Please visit
ctf.org/education to
download or request the
NFI Guide for Educators
brochure to share with your
child's school.



Teachers need parents to

- share responsibility in the education of their child
- understand the teacher's responsibility to all students in the class
- keep in mind what is reasonable when making requests
- instruct their child to respect and follow the rules of the school and classroom
- communicate closely and openly with the teacher
- ensure that their child is coming to school prepared with books, materials, and homework
- cooperate in reinforcing appropriate behavior and work production goals
- treat the teacher with courtesy and respect



Print this
page for
your child!

h o m e w o r k

Twelve Steps to Successful Homework Completion

One way in which you can help your child receive the best educational experience possible is to support his or her education at home.

Here are 12 steps to successful homework completion:



At school, the student

1. realizes an assignment is being given
2. writes down assignments
3. understands assignments
4. checks to see what to bring home at the end of the school day
5. brings home the assignments and necessary materials and textbooks



At home, the student

6. begins the homework
7. completes the homework
8. checks the homework for accuracy
9. puts the completed homework in a notebook



When the student returns to school, he or she must

10. take the homework back to school
11. keep track of it until the proper class
12. turn it in

homework

What Is the Homework Policy at Your Child's School?

To enable your child's success, ask questions to find out more about the homework policy at your child's school.

- What are the guidelines or homework policies for your school or school district?
- What are the teacher's expectations concerning homework?
- Is homework given every day?
- How much time should your child spend on homework each night?
- Does your school have programs to help students who are having trouble with homework?
- Are homework assignments available on the Internet?

Understanding the Purpose of Homework

For younger children, homework provides students with an opportunity to develop independent work skills. For older children, homework reinforces learning and helps your child master specific skills.



homework

What Is the Parent's Role in the Homework Process?

It's normal for parents to have feelings of anxiety, guilt, and worry that make them feel responsible for the completion of their child's homework. However, your role in the completion of homework is supportive. If parents are too active in the homework process and take on the role of remembering and reminding their children of their assignments, the child may become dependent. He or she may even rely on parents to "rescue" their homework. A cycle of dependency can be created as school pressures and fears of failure mount. Parents may eventually feel burdened and resentful. For children to develop independent work skills, it's critical to avoid or break the cycle of dependency. Here are a few tips to help you provide the structure at home needed to facilitate the homework process.

Establish a homework routine.

- Agree on which days of the week will be set aside for homework
- Determine how long your child will work on his or her homework
- Set up a designated space where your child will do his or her homework
- Organize materials
- Allow for "brain breaks"
- Ensure your child understands his or her responsibilities
- Understand your responsibilities (that is, monitor the homework process)

provide structure

homework

Create a homework space and include the following items:

- Mirror
- Timer
- Homework log sheet
- Fiddle toy
- Laminated list of homework buddies
- School classroom rules/procedures
- Backpack hook



Provide incentives to encourage homework skills.

- Use a token program to motivate your child to work on his or her homework
- Token charts (such as a dot-to-dot picture) may be used to track your child's daily progress
- Incentives for teens can include computer time, friend time, video games, or TV privileges
- Incentives can be tied into the plan by using earned allowance

Monitor the homework process.

- Monitoring is important to preventing potential lapses in the process
- The extent of monitoring will depend on the child's homework capabilities and the current homework expectations



Print this
page for
your child!

homework

Your child's role in the completion of homework is active, and he or she must accept the responsibility for completing the task. A school-to-home tracker like the one featured below may help your child to adequately prepare for homework while at school and successfully complete homework when at home.

Week of: _____ Student's name: _____

Before I leave school each day, I will check to make sure I have done the following:

	Mon	Tues	Wed	Thurs	Fri
1. Written down every assignment in my assignment book					
2. Collected and packed my books					
3. Gathered and packed all the materials I need to do my assignments					
4. Collected all notes needed to be seen by my parents					
5. Gathered and packed all my folders and notebooks					

Before I leave home in the morning, I will check to make sure I have the following:

	Mon	Tues	Wed	Thurs	Fri
1. All of my completed assignments					
2. All books I need					
3. All materials I need for school					
4. All signed notes					

homework

Teaching your child to record assignments on an assignment calendar worksheet may also help in the homework process.

For long-term assignments, have your child note the following on the calendar:

**The date work
is assigned**

**The date
it is due**

**The times that
he or she is going
to work on the
assignment**

How Much Is Too Much?


If the homework is a frequent cause of battles, tears, and frustration in your home, seek help! Let your child's teacher know your child's frustration tolerance in the evening. Request modifications and adjustments in his or her assignments.



schoolwork

What Your Child Should Know About Schoolwork

Ensure that your child understands that although neurofibromatosis is not an excuse for not doing schoolwork, it may be a reason for doing things differently. Completing homework is his or her responsibility, and it is important that homework comes first and fun comes later. Remind your child to use learning strategies and skills that have helped to make homework easier.



Above all, encourage your child
the effort itself is what counts!



Print this
page!

daily checklist

For Parents

School-to-Home Communication Daily Checklist

Keep this checklist in a place where you will see it every day, such as on your refrigerator or pinned to your family's calendar. This checklist will help you stay connected to your child's tasks, needs, and events in school.

- ☐ Check my child's schoolbag daily for any items that the school or teacher has sent home
- ☐ Read and refer to school district materials, such as back-to-school packets and core curriculum standards
- ☐ Make note of my child's big assignment due dates
- ☐ Mark special events on my calendar, such as library days, gym days, and field trips
- ☐ Read weekly or monthly letters from the teacher
- ☐ Use school-to-home trackers



activity to share with your child

10



Print this
page for
your child!

homework mix-up

Today in school, Sparx has received a homework assignment, but he has forgotten all of the steps he needs to take to complete it. Help Sparx by cutting out all of the steps below and putting them in the correct order.



Keep track of my completed assignment until I'm in the right class	Check my assignment to make sure I've completed it and that it's accurate	Write down my assignment, when it's due, and what class it's for
Make sure to bring my completed assignment back to school	Finish my assignment	Realize that an assignment is being given to me
Give my completed assignment to the teacher	Put my completed assignment in a safe place, such as in a notebook	Bring home my assignment and any materials I need to work on it
Make a list of everything I need to bring home at the end of the school day so that I can work on my assignment	Start my assignment	Make sure I understand my assignment and ask any questions I have about it

The answer key to this puzzle is on the next page.



Print this
page for
your child!

homework mix-up

Answer Key

1 Realize that an assignment is being given to me	2 Write down my assignment, when it's due, and what class it's for	3 Make sure I understand my assignment and ask any questions I have about it
4 Make a list of everything I need to bring home at the end of the school day so that I can work on my assignment	5 Bring home my assignment and any materials I need to work on it	6 Start my assignment
7 Finish my assignment	8 Check my assignment to make sure I've completed it and that it's accurate	9 Put my completed assignment in a safe place, like in a notebook
10 Make sure to bring my completed assignment back to school	11 Keep track of my completed assignment until I'm in the right class	12 Give my completed assignment to the teacher

notes

section

11

Educational Rights for Your Child
Part 1

Educational Rights for Your Child

part one

What Do I Do When My Child Is Having Difficulty at School?

It may be difficult to know where to begin when your child is having difficulty at school. A good starting point is to meet with your child's teacher. Get together and share your concerns and gain insight into any potential academic concerns. You can include others in your meeting if appropriate, such as the school administrator, counselor, or school psychologist. Together you can draft a written plan to address any potential concerns. Don't wait until you get a report card to assess the progress. Check in with your child's teacher every 2 to 3 weeks to ensure the plan is working as anticipated.

If the strategies above are unsuccessful, request a referral for an evaluation **in writing** to the school administrator. When you write a referral request letter, be sure to do the following:

- Describe your concerns about your child's academic and behavioral problems
- Include information about your child's medical or mental health diagnoses
- Keep a copy for your files

share your concerns



strategies

The school may respond to your request in several different ways. It may offer

- special accommodations (commonly referred to as Section 504 accommodations)
- an evaluation for special education
- no intervention (although your child may need private services)

Schools are required to consider a variety of information (including but not limited to parent information) in determining what support or interventions may be necessary to address your child's needs. A diagnosis of neurofibromatosis is helpful but not sufficient in determining eligibility for services. Eligibility is based on school-related behavior and performance and not on how your child functions outside of school.

support



section 504

Section 504 of the Rehabilitation Act of 1973 is designed to prevent any form of discrimination for eligible students who have a disability. For the purposes of 504, a “disabled person” is one who

- has a physical or mental impairment that **substantially limits** one or more major life activities
- has a record of such impairment
- is regarded as having such impairment

Parents may request accommodations to “level the playing field” for eligible students with a disability.

What Are Major Life Activities?

Some major life activities include the following:



Caring for oneself



Performing manual tasks



Walking



Seeing



Hearing



Breathing



Concentrating



Thinking



Communicating



Speaking



Learning



Working

section 504

What Types of Impairment Determine Substantial Limitation?

An impairment associated with substantial limitation is one that

- results in failure or underachievement when a child is compared with same-age nondisabled peers
- impacts a major life activity
- lasts at least 6 months
- will not improve without intervention from the school

Examples of Classroom 504 Accommodations

Tailoring homework assignments

Changing the way a test is given

Simplifying instructions about assignments

Providing a copy of peer notes

Supplementing verbal instructions with visual instructions

Using behavioral management techniques

Giving oral exams (tests given by spoken communication)

Using tape recorders

Providing computer-aided instructions

Providing nursing services to supervise administration of medication

Extending time needed to complete tests and assignments

Providing an extra set of books to keep at home

section 504

Section 504 Meetings

Many but not all school systems have annual meetings with parents to develop a child's Section 504 plan. Parental involvement is not required by federal law, but your preparation and follow-up for these meetings can have a major impact on the outcome. Pay attention to all the parent tips in the segment coming up on **Individualized Education Program** meetings. Although your rights may be different, the process is similar.





activity to share with your child

11



Print this
page for
your child!

“selfie” pop quiz

There are many important things to learn about in school, but Moxie says that it’s just as important to learn about yourself! Moxie calls this skill *self-awareness*! If you take the time to get to know yourself, you will have more confidence to do the things you’re great at and you will figure out the things you may need some help with. Take the quiz below. Be sure to share your answers with your parents or guardians.

For questions 1 through 4, circle the answer that best describes how you feel.

1. I know that I have a special condition called neurofibromatosis.
 - A. Yes
 - B. I think so
 - C. I’m not sure
 - D. No
2. I feel comfortable asking my teachers for help I need during class or with assignments.
 - A. Yes
 - B. I think so
 - C. I’m not sure
 - D. No
3. I feel good about my future.
 - A. Yes
 - B. I think so
 - C. I’m not sure
 - D. No
4. I feel comfortable telling other people, like my friends, about my neurofibromatosis.
 - A. Yes
 - B. I think so
 - C. I’m not sure
 - D. No





Print this
page for
your child!

"selfie" pop quiz

For questions 5 through 8, write your responses on the lines below.

5. Three things I am good at **in school**.

1. _____

2. _____

3. _____

6. Three things I need help with **in school**.

1. _____

2. _____

3. _____

7. Three things I enjoy doing **outside of school**.

1. _____

2. _____

3. _____

8. Three things I need help with doing **outside of school**.

1. _____

2. _____

3. _____



notes



section

12

Educational Rights for Your Child
Part 2

Educational Rights for Your Child

part two

Individuals With Disabilities Education Act

The Individuals With Disabilities Education Act, or IDEA, also known as special education, provides federal funding to school districts to provide eligible students with disabilities special education and related services to meet their individual needs. Each child must meet the eligibility criteria in at least 1 of 13 categories. The child must be in need of special education and related services, and the disabling condition must adversely affect the child's educational performance, creating an "educational need."

What Is Educational Need?

An educational need is established when a child shows evidence of a need for special education services through his or her inability to progress in a regular education program. An educational need is not limited to academics; it also pertains to behavior and social skills.

IDEA Disability Categories

- Autism
- Deafness
- Deaf-blindness
- Hearing impairment
- Intellectual disability
- Multiple disabilities
- Orthopedic impairment
- Other health impairment
- Serious emotional disturbance
- Specific learning disabilities
- Speech or language impairment
- Traumatic brain injury
- Visual impairment, including blindness



process

What Is the Process Used in Special Education?

Step 1: Referral

If a student is suspected of having a disability, his or her parents, or school personnel, must submit a referral (or request) for an educational evaluation in writing.

Step 2: Notice of Rights and Parental Consent

Once the referral is received, the district must provide the parents with a written notice of receipt and a copy of their rights. The district must also obtain a written consent from the parents to schedule and complete an evaluation.

Step 3: Conduct an Individual Initial Educational Evaluation

The evaluation will cover information about the student from a variety of sources. It will include background information and any outside evaluations, or medical information provided by the parents. The evaluation must be completed by the school within 60 calendar days after they receive written consent from the parents.

The written report should contain the following:

- A current status of academic achievement and related developmental needs
- A description of any problems the student has with school subjects and skills
- An assessment of how the child compares in his or her knowledge of the general education curriculum with other students of the same grade level
- The reason for the child's problems in school, including his or her relevant cognitive and behavioral concerns

process

Before the Individualized Education Program Meeting

- **Request** a copy of the evaluation report, read it, and meet with the teacher(s) or diagnostician before the **Individualized Education Program (IEP)** meeting to review the results of the tests
- **Decide** whom you will bring with you to attend the IEP meeting. You can bring an objective friend who can give a clear view of the problem, help you to take notes, and review them with you after the meeting. You can also bring an advocate who can help you better understand the process. Be prepared and always speak up for yourself and for your child
- **Read** your notice to see what issues will be discussed by the school and who will attend
- **Be prepared** to list the skills and behaviors you would like to see your child improve upon. **It may help to complete the sample worksheet on the next page and bring it with you**

Be prepared.





Print this page!

worksheet

Sample Worksheet to Take to an IEP or 504 Accommodations Plan Meeting

Purpose: To create a positive school and learning experience for _____

Strengths:

1. _____
2. _____
3. _____
4. _____

Learning differences:

1. _____
2. _____
3. _____

What happens to him/her in the classroom:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

What would help him/her in the classroom:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

Other: _____



process

Step 4: The IEP Meeting

You are a member of your child's IEP team. It is important to develop a positive working relationship with the team from the beginning. Thank the members for the work that they are doing on behalf of your child. No matter what, choose your battles wisely and be prepared to negotiate.

The discussion at the IEP meeting should address your child's current level of performance; academic, social, and behavioral development; and strengths and concerns. Measurable annual goals may also be addressed, as well as the method for assessing progress toward those goals. The educational services that will be provided will also be discussed, including transition planning should your child be 16 years of age or older.

The IEP team meets to determine your child's eligibility, appropriate "programming," and placement. Remember, your participation and input are critical, so don't hesitate to make suggestions for consideration by the team.

A decorative rectangular box with a patterned border. Inside the box, the word "process" is written in a green, lowercase, sans-serif font. The box is centered on the page, with horizontal dotted lines extending from its left and right sides.

process

Step 5: The IEP

The IEP is a written plan designed specifically for your child that outlines how he or she will be educated. The IEP must indicate what the school is going to do for the child, not what the child is going to do, and the plan must address all of your child's school-related needs, not just those for which he or she has been referred. If you disagree with the IEP, voice your concerns during the meeting and put them in writing after the meeting. Ask to see and receive a copy of the meeting minutes before you leave the meeting, and be sure that they reflect your concerns.

Step 6: After the Meeting

After the meeting, ensure that both you and the teacher have received a copy of the IEP that has been developed for your child. Set up routine communications with the school to keep track of your child's progress and challenges, and provide positive feedback when something has worked well for your child.

You are a valuable resource for the teacher, so stay actively involved and offer to help. Any skills learned at school need to be reinforced and supported at home. Be sure to read and save all progress reports and other notes sent home during the year to stay aware of how your child is doing.

Parent-teacher conferences can always be scheduled as needed. The IEP team must meet at least once a year to develop or revise your child's IEP, but you may request additional meetings if needed.

positive feedback



process

Section 504 or IDEA?

Section 504 provides a faster, more flexible procedure for obtaining accommodations and services for children with disabilities, particularly for children with less “serious” disabilities.

IDEA offers a wider range of service options and procedural safeguards and includes written parental consent and involvement.

Accommodations and modifications are meant to help your child within the area of his or her disability. They are **not** a reflection of your child’s intelligence or strengths. The goal is for your child to learn the age-appropriate grade level curriculum and to complete the schoolwork assigned by the teacher.

Tell your child whom he or she can ask for help. It is important for him or her to know whom to talk to when an accommodation plan or IEP isn’t being implemented. It is also important to remind your child that having a disability is not an excuse for bad behavior. Your child must be sure to understand and follow the student code of conduct.



activity to share with your child

12



Print this
page for
your child!

flashcards

It's important that you know whom to talk to at school if you need help with something or need something to be changed for you, such as a test or assignment.

On the cards below, write the names of people you can talk to when you need help. Ask your parents or guardians if you are not sure. Cut the cards out and keep them with you every day in a place where you will remember when you're at school, such as in a notebook or folder.



Name: _____

Who is this person? _____

What can this person help me with? _____

Where can I find this person? _____

Name: _____

Who is this person? _____

What can this person help me with? _____

Where can I find this person? _____

Name: _____

Who is this person? _____

What can this person help me with? _____

Where can I find this person? _____

section

13

Resilience, Transition to Adulthood,
and Future Success

resilience

Resilience is the ability to overcome hardship and adversity and to achieve good personal adjustment in spite of difficult circumstances. All children have this capacity. The purpose of this section is to give your family the tools to strengthen your child's resilience and ability to cope with neurofibromatosis.

In spite of your best efforts to manage the impact of your child's learning or behavioral difficulties, he or she may continue to experience daily challenges and setbacks that may persist into adolescence or even adulthood. Keep the following question in mind to help you stay on the path to resilience:

"In spite of my child's current struggles and setbacks, what can I do to help my child to still feel good about himself or herself?"

Protective Factors

Three categories of protective factors encourage the development of resilience:





relationships

Caring Relationships

A caring relationship provides frequent unconditional affection and lets your child know that he or she is important and matters in this world. Focus on your child's strengths and express empathy before trying to solve his or her problems. Try to validate your child's agenda and schedule quality time to strengthen your relationship.

High Expectations—Competency

Your expectations should be clear and positively stated, and they should be supported by structure at home and with positive discipline strategies. Parents' expectations are founded on the strengths, interests, hopes, and dreams of the youth, but they must also be based on their child's developmental abilities and skills. Use your expectations to communicate belief in your child.

- Are you focusing on how hard your child tries?
- Is your child doing better than before?
- Are you are taking the time to teach new skills?

express empathy

participation

Opportunities for Participation and Contribution

Give your child an opportunity to contribute at home by speaking his or her language and communicating in a way that he or she can understand.

Here are some tips to help encourage your child to participate successfully:

- Make difficult tasks easier by breaking them down into smaller tasks
- Show tolerance for making mistakes
- Demonstrate appropriate coping strategies
- Permit your child to make daily decisions; for example, about hair or clothes
- Allow a chance for your child to solve his or her problems
- Expect your child to contribute to family chores
- Involve your child in the development of house rules, routines, and priorities
- Allow his or her participation in group activities that require cooperation

Encourage problem solving and involvement in the decision-making process.

teen development

Typical Teen Development

During adolescence, your child is learning to define his or her own identity and moving from dependence to independence. Hormonal changes can trigger rapid physical development, sexual maturation, and emotional volatility, and your child may be experiencing alterations in sleep patterns and duration. As a teen develops more sophisticated reasoning abilities, he or she can be susceptible to the “pack mentality”—the development of a tribal mentality when one assumes the identity of the clique he or she hangs out with, and think of every member as a friend. The driving force behind the behavior of most teens is to fit in with their peers.

Challenges Teens With Neurofibromatosis Face

Parents who understand the challenges of adolescence will be better prepared to deal with this stage of life. When adolescence is coupled with neurofibromatosis, these challenges are far more difficult.

Teens often seek increased freedom from parental control and need greater involvement in decisions that affect them. They are concerned about peer acceptance, so teens may resist any decision that makes them feel different from their peers. The teenage years are emotionally volatile, so choose your battles wisely and keep in mind that this is a difficult time for your teen.

Focus on preserving your relationship with your teen by being flexible.

- Increase the focus on your teen’s agenda and values (for example, your teen wants to choose tech school over a 4-year college)
- Provide your teen with more choices and responsibility for his or her own decision making
- Include your teen as a partner in the problem-solving process

becoming an adult

Developing Skills to Becoming an Adult

The home environment lays out the blueprint for children who are developing into young adults. Parents are the teachers, teaching their children how to become adults.

Consider these questions:

- What kind of teacher do you remember who made a difference in your life?
- What kind of teacher do you want to be for your teen?

As children become teens and young adults, their desire for independence increases, as does the demand for good executive function skills, such as reasoning, prioritizing, planning, organizing, getting started, and managing time. Many teens with neurofibromatosis lack these necessary executive function skills. It is essential that they start early to learn how to set up systems that work and counteract the executive function deficits, as teens who fail to learn these skills will feel overwhelmed and may shut down.



teen development

What Your Teen Should Learn



Healthcare

- Scheduling doctor visits, seeking help as needed, and asking questions regarding his or her health problems



Education

- Learning to advocate for oneself
- Working toward a career
- Becoming independent



Life

- Learning how to find a job
- Managing money and independent living
- Developing social skills
- Maintain relationships with friends and family
- Engaging in a romantic relationship

money management

Teaching Your Child Money Management Strategies

The development of money management strategies is of high importance as your teen readies himself or herself for success in the adult world. Parents can begin these lessons early with the implementation of an earned allowance plan that teaches a child the value of money and mimics an adult work/payment scenario. Children can earn a set amount based on the chores or tasks they perform, and they can earn bonus cash for extra accomplishments.

As your child becomes a teen, you can help him or her to set up a simple budget and a bank account. You can assist your child in learning about the responsible use of a checking account and possibly even a prepaid credit card with a predetermined amount and usage plan.

What happens when you discover that your teen filled out a form and has received a \$5,000 credit line for a credit card?

Create a proactive plan for such a possibility. Tear up all credit card solicitations when they arrive in the mail. Set aside \$5 a week in a special account for your teen's future. If a teen overspends on a credit line, these savings can help to pay for the mistake.



self-advocacy

Student, Parent, and School Counselor Roles

A student with a disability must understand and be able to verbalize the nature of his or her disability. It is helpful if the student understands his or her strengths and weaknesses and is aware of how he or she learns best. A student needs to be a self-advocate. A self-advocate is able to speak up in logical, clear, and positive language to communicate with others about his or her needs. Self-advocates can take responsibility for themselves, and they are comfortable describing their disability and needs to others.

Remember—At the college or employment level, the individual with the disability holds the sole responsibility for self-identification and advocacy.

Counselors and parents must help the student with disabilities to

- gain self-knowledge
- understand their legal rights and responsibilities
- develop a transition plan for the postsecondary education or employment arena
- understand the college testing and application process



Print this
page for
your child!

s u c c e s s

Students' Keys to Success

Understanding and
accepting one's disability

Accepting responsibility
for one's own success

Preparing to work
collaboratively with others

Learning time
management skills

Possessing self-advocacy
skills

responsibility

j o b s

Finding a Job

Finding a job or career path of interest can be a difficult task. Begin by encouraging your teen to consider and answer the following questions:

- What are the things I like to do?
- What things do I do well?
- What kind of work environment works best for me?
- What types of jobs are *not* for me?

Once your teen has an idea of what area might be of interest to him or her, begin with a list of potential jobs and employers that may appeal to him or her and would be supported by his or her current skills. Ensure that your teen is prepared to complete a standard job application and write a short resume. Within these pieces be sure that your teen includes his or her accomplishments, awards, and extracurricular activities. Identify potential references and have your teen talk with each of them to receive their permission and current contact information.

Once an interview has been scheduled, try to prepare a list of some standard interview questions for your teen to consider and practice answering. Talk to your teen about proper dress and grooming for an interview. Finally, cheer him or her on throughout the employment process, and celebrate when your teen becomes employed!

Job acquisition is a
huge accomplishment!

the road ahead

Moving Forward

What My Teen Should Know

You have stood beside your child over the years, teaching and guiding him or her along the way. Be proud of yourself. Have confidence that you have instilled good values in your teen and adequately prepared him or her for the road ahead.

Some thoughts for your teen might include the following reminders:

- Neurofibromatosis is a lifelong disorder
- Learning disabilities and behavior problems can be and are treated successfully
- Medication management is extremely important
- Being a self-advocate is an important goal to work toward
- Managing neurofibromatosis involves many facets, including learning to navigate school, money, and future plans
- Don't hesitate to reach out for help. There are coaches and experts in the field of neurofibromatosis who can help those with the disorder manage their daily life activities



celebrate success

Next Steps for Your Family

The material presented within this manual is designed to support you through your challenges as a parent of a child who has neurofibromatosis. It is up to you to decide how to implement and follow what you have learned from this material. Each family, and each child, is different, and each may require a different solution to the challenges he or she faces. What is most important is that you know that you are not alone. There are support groups available that may help you proceed down the road ahead. You can also participate with and receive guidance from the Children's Tumor Foundation (CTF) and Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD).

New information is always becoming available to help us further understand neurofibromatosis and its challenges. Continue your learning over time to give your family the best opportunity as you move ahead. Most important, celebrate your success—the success of your parenting, the success of your family, and the success of your child!

You might even consider helping other families who have a child with neurofibromatosis.





notes





activity to share with your child

13



Print this
page for
your child!

empower yourself

As you get older, it's important that you know not only **what** you need to be successful in school and in the future but also **how** to get it. Moxie and Sparx call this skill self-advocacy!

In the space below, describe a situation that might require you to request adjustments or changes you need to complete a task. Think about what you need to do to get them. This situation could be related to a class you're in now, or a situation you see in your future, such as finding a job.

Describe the place or situation:

What type of accommodations or help would you request?

Why would you need these accommodations?



Print this
page for
your child!

empower yourself

Whom would you speak with about getting these accommodations?

.....

.....

.....

What should you remember about how you talk to these people? (For example, how you use your body language, tone of voice, word choices, etc)

.....

.....

.....

Remember this term!

Accommodations = any adjustments or changes you may need to complete a task.



acknowledgment

The Children's Tumor Foundation thanks CHADD for their assistance in the development of this guidebook



As home to the National Resource Center on ADHD, funded by the U.S. Centers for Disease Control and Prevention, CHADD is the most trusted source for reliable, science-based information regarding current medical research and ADHD management, and offers comprehensive programs and services at both the national and local levels.

CHADD is the leading resource on Attention-Deficit/Hyperactivity Disorder (ADHD).

CHADD Programs and Services

- Parent to Parent Program
- Teacher to Teacher Training Program
- Local Support Groups
- Public Education and Outreach
- Advocacy
- National Resource Center
- Annual International Conference
- Attention Magazine
- ADHD News
- Attention Connection
- Ask the Expert Webinar Series
- ADHD Helpline
- Young Scientist Awards

CHADD provides support, training, education, and advocacy for the **17 million children and adults** in the United States living with ADHD, their families, educators, and healthcare professionals.

Learn More

We invite you to learn more by visiting **CHADD.org** or contacting us at 301-306-7070.

4601 Presidents Drive, Suite 300
Lanham, MD 20706



Founded in 1978, the Children's Tumor Foundation is a highly recognized national nonprofit 501(c)(3) organization dedicated to finding treatments for neurofibromatosis (NF).

Our Mission: Drive research, expand knowledge, and advance care for the NF community.

Our Vision: End NF.

To become involved, learn about Foundation activities in your area, or make a donation, please visit our website at **ctf.org**.

Children's Tumor Foundation
ctf.org
info@ctf.org
1-800-323-7938

