

Communication Skills of Individuals with NF1

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- Communication Disorders (CD) frequently occur and are under-identified in children with Neurofibromatosis (NF) type 1 (NF1)¹.
- At this time, the exact cause of CD in NF1 is unknown.
- Individuals with NF1 may have an IQ that is normal/close to normal, but still exhibit a CD.
- They may also under-perform on cognitive tests that involve using language (i.e., following directions, answering questions, etc.)
- Some children with NF1 exhibit a learning disability, impaired language, or difficulties with reading and/or writing².

Individuals with NF may exhibit different types of Communication Disorders (CD)³:

Area	Example of a Concern
Expressive or receptive language disorder	Difficulty producing (expressive) or understanding (receptive) language.
<ul style="list-style-type: none"> • Vocabulary (understanding or producing) 	Trouble understanding what words mean.
<ul style="list-style-type: none"> • Remembering words 	Trouble with recalling or remembering a specific word.
<ul style="list-style-type: none"> • Grammar (when speaking or writing) 	Problems using correct grammar in oral or written language (e.g., a child says, “ <i>I <u>goed</u> to school</i> ” instead of “ <i>I went to school.</i> ”)
Speech sound production/Articulation	Speech sound disorder, or the incorrect use of sounds (e.g., child says “ <i>dough</i> ” for “ <i>go</i> ” or “ <i>tup</i> ” for “ <i>cup</i> .”)
Fluency	Stuttering, or an inability “to get the words out.”
Voice	Loud vocal volume or a harsh or “creaky” voice quality.
Resonance	Nasal sounding voice quality.
Social Communication or Autism Spectrum Disorder	Not responding appropriately in social situations, inability to take another person’s perspective, or rigidity in behavior.
Reading	When individuals cannot read, have difficulty reading grade-appropriate text or don’t like reading because they feel like they are “not good at it.”
Phonological Awareness skills	Inability to segment words into parts, trouble with producing or identifying rhyming words, or lack of sound knowledge.
Writing/spelling	Difficulties with printing or using cursive writing. Problems using the correct spelling of words.
Hearing	Ability to hear sounds of different pitches or volumes.
Auditory processing	Individual has passed a hearing evaluation but has difficulty processing information that is heard.

¹ Thompson H, Viskochil D, Stevenson D, Chapman K. 2010. Speech–language characteristics of children with neurofibromatosis type 1. *Am J Med Genet Part A* 152A:284– 290.

² Coutinho, V., Kemlin, I., Dorison, N., Billette de Villemeur, T. (2016). Neuropsychological evaluation and parental assessment of behavioral and motor difficulties in children with neurofibromatosis type 1. *Research in Developmental Disabilities*, 48, 220-230.

³ Thompson, HL., Stevenson, DA., Redmond, SM., Smith, BL. & Viskochil, DH. Communication disorders associated with neurofibromatosis type 1. *In Neurofibromatosis Type 1* by Karajannis, MAA & Allen, J. (eds.) 2013. New York, NY: Nova Science Publishers.

Help for Parents:

- Parents can monitor important communication milestones, such as:
 - **Child's** production of his/her first word around 12 months of age.
 - **Child's** production of two-word combinations at approximately 2 years of age.
 - Learning to read around the time of school entry.
 - Child is reading to learn by third grade.
 - Child exhibits appropriate social communication skills for their age (i.e., *Does the young child use appropriate greetings, make eye contact, play with others? Does an older child understand jokes?*)
 - If the child is learning more than one language, it is important to seek assistance if the child has trouble in their primary language or if parents are concerned about the **child's** communication skills.⁴
- If parents are concerned with the communication skills of their toddler or preschool-aged child, they can contact their local primary care provider or physician to obtain a referral to a Speech-Language Pathologist (SLP) who works in an early intervention setting or local head start program.
- Many schools also offer services to children before they enter Kindergarten. **Children's** communication develops best when they receive early intervention.
- Once children are enrolled in school, parents can contact the school to ask about SLP services available through the district. Collaboration with school personnel can allow students to acquire appropriate educational support plans, such as an Individualized Educational Plan (IEP), 504 plan or neuropsychological testing (see [NF1 Information for Teachers](#)).
- Parents of children who are homeschooled can contact the school in their catchment area to obtain information about eligibility for special education services. However, you may need to travel to the school for appointments.
- School-aged children may be able to access additional SLP services beyond those provided through the school district. Many local universities that have SLP or Communication Sciences and Disorders programs have clinics that provide assessment and intervention services. Oftentimes, these services are substantially cheaper than services provided through a local private practice. Parents should contact their insurance company to determine if SLP services are covered.

Who are speech-language pathologists?

- Speech-Language Pathologists (SLPs) or '**speech therapists,**' are professionals who provide services for the prevention, assessment, diagnosis and treatment of disorders of communication and/or swallowing. Because the same mechanism that is used for speaking is also used for eating and drinking, SLPs provide assessment and intervention services for swallowing.
- SLPs work in hospitals, schools, private practices and/or long-term care facilities.
- Most SLPs provide individual or group services, but some work via telepractice, allowing families to have greater access.
- SLPs are part of a team of allied health care professionals; they collaborate with physicians, psychologists, physical therapists, occupational therapists, audiologists, respiratory therapists, nurses, medical geneticists/genetic counselors, and nutritionists, to name a few.
- SLPs have graduate-level academic and clinical training in speech-language pathology or communication sciences and disorders. They are required to have at least a **master's** degree to practice in the United States.
- Some SLPs earn a Ph.D because they are interested in researching how different therapies work and understanding disorders more fully.
- SLPs provide assessment and intervention services for individuals across the lifespan - from infancy through to the geriatric years.
- Sometimes Speech-Language Pathology Assistants (SLPAs) provide intervention services in addition to assisting the SLP with other duties. SLPAs are supervised by SLPa and cannot replace them.
- Please see [the American Speech-Language Hearing Association](#) (ASHA) for more information about the field of speech-language pathology.

Where to go for more information:

1. For information about Speech-Language Pathology or Audiology, please see ASHA at <http://www.asha.org/public/>
2. To find a speech-language pathologist or audiologist in your area: <http://www.asha.org/profind/>
3. To learn more about pediatric feeding concerns: www.feedingmatters.org
4. To find out more about Neurofibromatosis and local events and support groups, see: www.ctf.org

⁴ Roseberry-McKibbin, C. *Multicultural students with special language needs*, 4th ed. 2014. Academic Communication Associates. Oceanside, CA.