

Speech and Language Therapy

for the Child with Prader-Willi Syndrome

How Can a Speech and Language Pathologist Help?

The goal of the Speech Pathologist is to help the child become a more functional communicator. Important goals may be to increase vocabulary skills, improve articulation, length of utterances and grammatical sentences, improve socially appropriate communication behaviors such as eye contact, initiating and maintaining conversation, and turn-taking.

Interventions must be individualized because of variations in the communication skills of persons with PWS. Treatment will vary depending on the child's age, diagnosis and/or severity of clinical symptoms and the child's cognitive ability. The Speech Pathologist's techniques will be geared toward improving any or all components of speech and language that appear to be affected.

The speech pathologist may suggest using augmentative communication techniques to facilitate communication. These techniques include:

- Manual communication (Sign Language)
- Picture or symbol boards
- A voice output device

These alternative forms of communication are often transitional steps to the development of speech and language. In many cases, augmentative techniques increase overall communication and may reduce the level of frustration for both child and caregivers.

Oral-motor therapy during infancy can help "wake up" and improve the function of the muscles associated with pre-speech. Many speech pathologists are trained to make clinical observations of swallowing, assess oral-motor and feeding issues and provide recommendations for swallow study evaluations and treatment.

How to Locate a Speech Pathologist

Speech/language professionals work in several types of facilities such as:

- Regional Centers
- Public schools
- Hospitals and clinics
- Rehabilitation centers
- Colleges and universities
- Private Practice
- State and federal agencies
- State & local health departments

Your Regional Center can help you find and fund a qualified Speech and Language Pathologist. Your school district can assist you with your child's speech and language needs from age three to twenty-two years. Your private insurance company may also be able to assist you with therapy.

For help locating a qualified Speech and Language Pathologist near you contact the American Speech-Language-Hearing Association at 800.638.8255 or www.asha.org.



Prader-Willi California Foundation is a non-profit 501(c)(3) corporation established in 1979. An affiliate of the Prader-Willi Syndrome Association (USA), PWCF is dedicated to supporting individuals with Prader-Willi syndrome, their families, and the professionals who serve them.



Prader-Willi California Foundation

1855 First Avenue, Suite 201, San Diego, CA 92101
310.372.5053 • 800.400.9994 (Toll Free in CA)
info@pwcf.org • www.pwcf.org

An Affiliate of Prader-Willi Syndrome Association (USA)
800.926.4797 • info@pwsausa.org • www.pwsausa.org



Prader-Willi California Foundation

Supporting People with Prader-Willi Syndrome

Why are Speech and Language Therapy Important for Children with Prader-Willi Syndrome?

Effective use of speech and language skills allows people to express their needs, wants, thoughts and feelings and to receive and understand information about the world around them. Communication affects one's ability to interact and connect with others in play, work, and other aspects of daily living. The ability to communicate greatly influences quality of life.

Children born with Prader-Willi Syndrome (PWS) often have varying degrees of difficulty with oral motor skills and the development of speech and language skills. While parents can help stimulate language development in many ways, the skills of a trained Speech and Language Pathologist are often necessary to help children with PWS achieve their full potential.



What are the Components of Speech and Language?

Receptive Language is the ability to understand what is being said by others.

Expressive Language is the ability to express one's thoughts, feelings, wants and needs.

Articulation is the ability to produce speech sounds.

Fluency is the ability to control the rate and rhythm of speech.

Voice is the ability to generate an appropriate vibration as the air flows through the voice box.

Prosody refers to intonation, stress pattern, loudness variations, pausing, and rhythm.

What Impact Does Prader-Willi Syndrome Have?

Communication disorders are common in people with the syndrome as PWS can impact all aspects of speech and language development. During infancy, hypotonia (low muscle tone) and difficulty coordinating and sequencing motor movements may interfere with sucking, swallowing, chewing and babbling, all prerequisite skills for the development of speech and language. PWS may cause structural abnormalities such as a high palate and decreased saliva production. PWS can interfere with the brain's ability to summarize and/or sequence events or stories in order to communicate them effectively.

When Should You Seek Help?

Early assessment and intervention are critical to the development of functional communication. Parents are strongly encouraged to begin oral-motor therapy in infancy to assist with feeding and the acquisition of the oral-motor skills necessary for babbling and speech.

If receiving the diagnosis later in childhood, a speech and language assessment should be made as soon as the diagnosis is made.

Global praxis problems, i.e., gross and fine motor planning and coordinator and/or a gap between the child's receptive and expressive language skills, indicate the need to assess for Childhood Apraxia of Speech.

Who Can Evaluate Speech and Language Functions?

A Speech and Language Pathologist who is trained at the master's or doctoral level is the best qualified professional. Speech Pathologists must meet certain standards of competence in order to be licensed, including public school therapists. The Speech Pathologist should hold a certificate of clinical competence from the American Speech and Hearing Association and/or be licensed by the state or education system.

Some pediatric occupational therapists have specialized training in feeding and/or sensory issues affecting oral-motor development.

Childhood Apraxia of Speech

Children with PWS often have a specific speech and language disorder called Childhood Apraxia of Speech (CAS). This particular speech disorder interferes with oral-motor coordination (the prefix 'dys' means "difficult;" 'praxis' means "movement;" thus the word literally means "difficult movement"). Children with PWS often have global praxis problems - difficulty coordinating fine and gross motor movements as well as speech movements and language sequencing.

While hypotonia (low muscle tone) may make it difficult to move the muscles to produce the desired sounds (diagnosed as "dysarthria"), for a child with CAS the brain has difficulty sequencing and coordinating the muscles of the mouth and the respiratory system in the ways necessary to produce clear, smooth speech as well as organized, concise language. If a child has CAS, treatment *must* be specific to CAS. Some speech therapists believe that CAS cannot be diagnosed until speech begins. Whether or not one believes the diagnosis can be made, is recommended that therapists treat the child with PWS *as if* they have CAS until such time as they can diagnose it. This is because treating a child who does not have CAS with techniques specific to CAS does no harm. On the other hand, children who have CAS and are *not* treated specifically for CAS (i.e., treated for some other speech disorder such as Developmental Speech Delay) *will likely make inadequate or no progress*.

Treatment for CAS may include the PROMPT© System which stands for "Prompts for Restructuring Oral Muscular Phonetic Targets." This is a specialized method of treatment for motor disorders designed to help the child gain voluntary control over their motor-speech systems.

For more information about Childhood Apraxia of Speech visit the website www.apraxia-kids.org.