

PWWSA^{U.S.A.}

**Speech and
Language
&
Prader-Willi
Syndrome**



Why are Speech and Language Important?

For children born with Prader-Willi syndrome (PWS), the development of speech and language skills is often delayed and problematic. Parents can stimulate language development in many ways, but may require professional help for a child with PWS to achieve his or her full potential in the use of speech and language.

Adequate speech and language skills contribute greatly to learning daily living tasks, to the educational progress, to personal growth, and to playing, working and living with others. Effective use of speech and language allows persons with PWS to express needs, thoughts and feelings, and to receive information about the world around them. Limited skills may radically influence the quality of life.

What are the Components of Development?

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

Expressive Language: the ability to express one's own needs, thoughts and feelings.

Articulation: the capacity to move the tongue, lips, jaw and palate as air flows through the voice box and out the mouth and nose, resulting in speech that is understandable.

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

Voice: the ability to generate an appropriate sound wave or vibration as the air flows through the voice box.

What Impact Does PWS Have?

PWS can impede all aspects of speech and language development. When intellectual capacity is limited, both receptive and expressive language and the ability to develop speech sounds (articulation) are affected.

Clear, intelligible signals are essential for communication. Unintelligible speech can be due to any underlying neuromotor problem which, in PWS, may be hypotonia (low muscle tone). Hypotonia can affect the rate of speech, quality of the voice, and the ability to coordinate movements of the tongue, lips, jaws and palate. Speech may be slowed, slurred and/or nasal.

Any one of these problems or a combination thereof results in the decreased ability to communicate. Therefore, persons with PWS are at risk for developing some type of speech and language problem - with accompanying frustration.

When Should You Seek Help?

Seek help when the diagnosis of PWS is made or, in instances where the diagnosis is uncertain, when there is some indication of delay in speech and language development. Early assessment and intervention are critical to the development of functional communication. Even an infant can be assisted with improving receptive and expressive language and the oral-motor skills needed early for feeding and later for speech.

Who Can Evaluate Speech and Language Functions?

A speech/language pathologist who is trained at the master's or doctoral level is the best qualified professional. The pathologist should hold a certificate of clinical competence from the American Speech and Hearing Association and/or be licensed by a state.

Public school speech therapists also may be qualified professionals, may or may not have a master's degree or be certified by the ASHA, but they must meet certain standards of competence in order to be licensed.

How Can a Speech and Language Pathologist Help?

The goal of the pathologist is to assist the child in becoming a more functional communicator. Interventions must be individualized because of variations in the communication skills of persons with PWS. The pathologist's techniques will be geared toward improving any or all components of speech and language that appear to be affected.

Clinical methods for helping will vary depending on the age, severity of clinical symptoms, and cognitive ability.

In young children whose speech is delayed, the pathologist may suggest using augmentative communication techniques such as:

- ◆ manual communication (signing);
- ◆ picture or symbol boards; and
- ◆ a voice output device (a portable computer that speaks a word or phrase when the child presses a picture or symbol).

Do not be dismayed if any of these are suggested. These alternate forms of communication are merely 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.

Individuals with PWS often have articulation errors and reduced intelligibility in their speech. The pathologist can evaluate the child's abilities in sound development sequence and then use a variety of techniques to improve pronunciation.

Other important goals may be to increase vocabulary skills, to improve patterns of word formation and grammatical sentences, and to work on socially appropriate communication behaviors such as eye contact, initiating conversation and giving compliments.




How to Locate a Speech Pathologist

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

- ◆ public schools;
- ◆ hospitals and clinics;
- ◆ rehabilitation centers;
- ◆ colleges and universities;
- ◆ private practice;
- ◆ state and local health departments; and
- ◆ state and federal agencies.

For assistance in locating a qualified speech/language pathologist in your area, write or call:

American Speech-Language-Hearing Association (ASHA)
10801 Rockville Pike
Rockville, MD 20852
(800) 638-8255
(301)897-5700



The Prader-Willi Syndrome Association (USA) was formed in 1975 in order to provide a vehicle of communication for parents, professionals and other interested citizens. It is an organization dedicated to the sharing of experiences in how to cope with the syndrome. Chapters of PWSA(USA) are located in most states and are available for support, education and advocacy.

An annual national conference, a bi-monthly newsletter entitled The Gathered View, which incorporates contributions from members as well as professional advice and a wealth of other written materials and publications on Prader-Willi Syndrome, are all part of PWSA's effort to carry out its mission.

Supported solely by membership fees and donations, Prader-Willi Syndrome Association (USA) has made a difference in the lives of many affected by this unique syndrome. YOU, TOO, CAN HELP. Donations and membership applications may be sent to the address below.

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